In 2001, nine organizations with an interest in lung cancer came together and formed the Global Lung Cancer Coalition. Today, the GLCC comprises of 34 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

WORLD CONFERENCE ON LUNG CANCER

In September this year, the 16th World Conference on Lung Cancer took place in Denver, USA.

It is the world’s largest meeting dedicated to lung cancer and other thoracic malignancies, and it welcomed more than 7,000 delegates from over 100 countries to discuss the latest developments in thoracic malignancy research.

Among this impressive number were members of the GLCC. They met to share news and ideas, connect with people from other cancer organisations and learn from the many scientists, clinicians and other health professionals who spoke at the event.

Here, Jennifer King, Director of Science and Research for Lung Cancer Alliance, highlights some of the interesting topics covered in the talks program:

Early detection – it was revealed that a lot of work is being carried out to understand who should be screened by low-dose CT scans and when these scans should take place, as well as what should be done if an indeterminate nodule is identified but it’s not clear if it’s cancer.

There were also a series of talks on new technologies that could test blood, sputum or someone’s breath to help with these issues. These are not ready in clinic yet but are on the horizon.

Continues on page 2
WORLD CONFERENCE ON LUNG CANCER

Continued from page 1

Immunotherapy – there was an update on nivolumab. This revealed that patients with squamous cell carcinoma who initially responded well to the drug were still doing well up to two years later. See page 7.

Data was presented that showed combining two different types of immunotherapies may result in better response rates than if a single drug is administered. This is done before a patient undergoes chemotherapy, and there is a lot of interest in studying the application of immunotherapies in this way.

The changing face of lung cancer – two different studies, one from the UK and one from the US, showed that the incidence of non-small cell lung cancer in never-smokers is increasing. These never-smokers tended to be younger and female. See page 6.

A different study on people under 40 with lung cancer showed that their cancers tended to have higher levels of changes in genes such as EGFR and ALK.

Taken together, all of these studies showed that lung cancer is not just a smoking-related disease, and there needs to be more public education and increased awareness about who can be affected.

SPOTLIGHT ON GLCC

The first of a regular column that highlights the efforts of member organizations to raise awareness of the GLCC and how members are working together across the globe.

Aoife McNamara from the Irish Cancer Society gave an interview to News Medical about the affect of lung cancer on a person and the work of the GLCC.

Please click here to read the full interview.

Maureen Rigney of Lung Cancer Alliance in the US presented posters on the GLCC at international conferences to raise awareness of our vital work.

One goal, different purposes: How charities around the globe help the lung cancer community was presented at the joint American Psychosocial Oncology Society/International Psychosocial Oncology Society annual meeting in Washington DC, USA in July 2015.

The Global Lung Cancer Coalition: Finding common ground in our diversity was presented at the annual meeting of the International Psychosocial Oncology Society in Lisbon, Portugal in September 2014.

A collaboration between the Roy Castle Lung Cancer Foundation in the UK, LungFoundation Australia and Lung Cancer Alliance in the US led to facilitators of lung cancer support groups answering questions about their work.

This resulted in the Lung Cancer Alliance publishing the Lung Cancer Support Group Troubleshooting Guide in August 2015.

NEW RUSSIAN MEMBERS

In August this year, GLCC was delighted to offer joint membership to the Russian organisations Equal Right to Life and Movement Against Cancer.

Equal Right to Life is a non-governmental organisation established in 2006 by Russian oncologists and volunteers. It aims to implement significant healthcare initiatives to fight against cancer, as well as support other social, charitable, cultural, educational and scientific projects to benefit the people of Russia.

www.ravnoepravo.ru

Movement Against Cancer was established in 2008 by oncologists, patients and their relatives. It has affiliation organisations in more than 15 Russian regions.

The objectives of Movement Against Cancer include improving the quality of cancer care provided to people living in Russia; raising awareness of cancer and symptoms to increase early diagnoses; advocating on behalf of patients so they receive high-quality treatment; and working with authorities to improve access to the latest cancer treatments.

www.rakpobedim.ru

The 17th World Conference on Lung Cancer takes place in Vienna, Austria, on 4–7 December 2017.

LUNG CANCER AWARENESS MONTH 2015

In November 2015, many members of the GLCC used Lung Cancer Awareness Month to focus on lung cancer issues and lung health in their country. Here are just some of the highlights:

LungFoundation Australia

LungFoundation Australia encouraged people to host a Shine a Light event in November to raise awareness of lung cancer, remember those lost to the illness and bring together survivors to share their stories.

Event suggestions included a morning tea with your family, a walk with friends, a BBQ or sausage sizzle, or a cake stall at your school.

Canadian Lung Association

The Canadian Lung Association used Lung Cancer Awareness Month to rally Canadians to help fund new breakthrough research so no one will have to struggle to breathe.

Its Breathing as One campaign aims to reduce risk from lung disease, discover cures, save lives and improve the quality of life of all Canadians.

Women Against Lung Cancer in Europe

During November, WALCE distributed information to raise awareness of lung cancer and promoted a toll-free number for people to ring if they had questions or concerns.

The organization also supported a make-up program in Italy to help women manage the visible signs of cancer and treatment, helping to improve their self-esteem and boost confidence.

British Lung Foundation

British Lung Foundation used Lung Cancer Awareness Month to launch the report Tackling emergency presentation of lung cancer.

It features a series of recommendations for the UK government that will make significant improvements to lung cancer diagnosis and care.

Free to Breathe created signs for Lung Cancer Awareness Month

Commuters on the London Underground were given a surprise wake-up call when an impromptu chorus broke out on the Jubilee Line with a “coughing” beat box to mark Lung Cancer Awareness Month.

The throat-hacking performance was carried out by Roy Castle Lung Cancer Foundation, Boehringer Ingheim and the Beatbox Collective to help raise awareness of a persistent cough as one of the main symptoms of lung cancer.

Lung Cancer Alliance

Lung Cancer Alliance encouraged people in the US to get involved with its seventh annual Shine a Light on Lung Cancer event in November.

It’s the largest coordinated awareness event for lung cancer in the United States, and more than 300 events were expected to take place.

Free to Breathe

As part of Lung Cancer Awareness Month, Free to Breathe asked people to “Take the Pledge” and do at least one of three things during the month of November:

- Inform – deliver lung cancer symptoms bookmarks to local libraries.
- Donate – give just $2 toward Free to Breathe’s national paper lungs campaign.
- Share – post an “unselfie” on social media to tell people why raising awareness of lung cancer is so important.

Roy Castle Lung Cancer Foundation

As part of Lung Cancer Awareness Month, Free to Breathe encouraged people to “Take the Pledge” and do at least one of three things during the month of November:
OUR MARATHON MAN

Peter Czanyo was diagnosed with lung cancer in 2003 and had part of his left lung removed. Since then he’s taken on many tough challenges to raise awareness of lung cancer and the need for more research into the illness.

Peter’s next challenge is a 100km trek in the Andes mountains in February 2016. Please email him at peter.cza@gmail.com to wish him the best of luck.

LEADING THE WAY IN ITALY

ALCASE Italia has been working hard throughout 2015 to improve the lives of people affected by lung cancer.

In November, it hosted the first ever meeting in Italy of people with lung cancer, carers and lung cancer advocates. Its aim was to help people share experiences and information, support each other and develop friendships.

ALCASE Italia has also been busy urging the Italian health service to fund annual low-dose CT scans for high-risk individuals. This follows the National Lung Screening Trial in the US, which led to a 20% reduction in lung cancer mortality after high-risk individuals received an annual low-dose CT scan.

LUNG CANCER RESEARCH IN THE UK

In the UK, GLCC members continue to fund world-leading research to treat lung cancer and improve the health and wellbeing of people diagnosed with the illness.

British Lung Foundation
- Professor Caroline Dive at the University of Manchester has received funding for a two-year project looking at why lung cancer becomes resistant to drugs over time and re-emerges. This involves taking a blood sample when a person first visits an oncology clinic and again when their tumor fails to respond to treatment.

- Dr John Marshall at the University of London has received funding for a three-year project into the development of lung cancer treatments that target the integrin αvß6. New evidence suggests that integrin αvß6 helps lung cancer cells to divide, survive and spread.

- Professor Mike Grogg at the University of Southampton has received funding for a two-year project to investigate how increased physical activity before and during chemotherapy may benefit people with advanced lung cancer. Studies have shown that exercise can reduce fatigue and a lack of energy in cancer patients.

MILITARY VETERANS CAMPAIGN

In November, the Lung Cancer Alliance launched a campaign to increase early diagnoses in men and women who have served in the military, who have a higher risk of developing lung cancer than civilians.

The campaign features a series of awareness materials and stories from military veterans who have been diagnosed with lung cancer. They encourage ex-members of the armed forces to visit atriskforlungcancer.org to find out their risk of lung cancer and where to go to get screened.

INNOVATION PRIZE WINNERS

In the last edition of Unity, we told you about Free to Breathe and Bonnie Addario Lung Cancer Foundation’s challenge to increase the number of patients participating in cancer clinical trials.

After considering over 100 entries from all over the world, the judging panel chose to award grants to the following three entries:

First prize ($20,000)
- Match Point: Matching Patients and Trials Via EHR
  - A system that reads patients’ electronic health records to automatically match them to clinical trials.

Second Prize ($5,000)
- Fast, Fun & Friendly: Build Trust Before Research Participation
  - A system to help patients take part in clinical research from the comfort of their own homes.

People’s Choice Award ($5,000)
- Meet NORA (Network Oriented Research Assistant)
  - A system that reads patients’ pertinent videos.
LACK OF PERSONALIZED TREATMENTS

A global survey of lung cancer oncologists has shown that despite 81% of newly diagnosed advanced non-small cell lung cancer patients being tested for EGFR mutations, a significant number did not go on to receive personalized treatments for their cancer type and mutation subtype.

The survey highlighted that almost one in four advanced NSCLC patients are started on first-line treatment before their mutation test results are available, with significant differences between regions (range: 12% in Asia to 30% in Europe).

The main reasons for not testing all patients, aside from tumor histology, were insufficient tissue/uncertainty of sufficient tissue, poor patient fitness, and test results taking too long to come back. In addition, half of all oncologists (51%) stated that their treatment decision was not affected by EGFR mutation subtype. Again, there was significant variation between regions (range: 28% in Asia to 60% in Europe).

Dr Matthew Peters, chair of the Global Lung Cancer Coalition, said, “This research clearly shows there are patterns of care in the evaluation and initial treatment of lung cancer which do not always include EGFR testing.”

From BusinessWire, 17 April 2015. Click here to read the full news story.

STARVING LUNG CANCER

Scientists have identified a new way to stop the growth of lung cancer cells, by blocking their ability to use alternative sources of nutrition.

A team of scientists from McGill University in Montreal, Canada, Washington University in St Louis, USA, IITMO University in St Petersburg, Russia, and the University of Bristol in the UK studied the response of cancer cells to reduced availability of glucose, the main fuel source for most cancer cells.

The group chose to experiment with non-small cell lung cancer patients being tested for EGFR mutation subtype. Again, there was significant variation between regions (range: 28% in Asia to 60% in Europe).

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Dr Matthew Peters, chair of the Global Lung Cancer Coalition, said, “This research clearly shows there are patterns of care in the evaluation and initial treatment of lung cancer which do not always include EGFR testing.”

From BusinessWire, 17 April 2015. Click here to read the full news story.

LANDMARK E-CIGARETTE REVIEW

An expert independent evidence review published by Public Health England has concluded that e-cigarettes are significantly less harmful to health than tobacco, and have the potential to help smokers quit smoking.

Key findings of the review include:

- The current best estimate is that e-cigarettes are around 95% less harmful than smoking.
- There is no evidence so far that e-cigarettes are acting as a route into smoking for children or non-smokers.
- Nearly half of the population of England (44.8%) don’t realise e-cigarettes are much less harmful than smoking.

Professor Kevin Fenton, Director of Health and Wellbeing at Public Health England said, “E-cigarettes are not completely risk free but when compared to smoking, evidence shows they carry just a fraction of the harm.

“The problem is people increasingly think they are at least as harmful, and this may be keeping millions of smokers from quitting. Local stop smoking services should look to support e-cigarette users in their journey to quitting completely.”

From BusinessWire, 17 April 2015. Click here to read the full news story.

RISE IN NEVER-SMOKER LUNG CANCER CASES

New research has revealed that never-smokers account for a growing percentage of aggressive lung cancer cases in the United Kingdom and the United States.

In a British study, researchers found that over seven years the proportion of UK never-smokers with non-small cell lung cancer jumped from 13% to 28%. These findings were based on the medical records of 2,170 UK patients who underwent surgery for lung cancer between 2008 and 2014.

Similarly, a study of lung cancer patients at three US hospitals reported that never-smokers accounted for a growing percentage of non-small cell lung cancer patients between 1990 and 2013. These never-smokers with lung cancer were more likely to be women, the researchers said.

From WebMD, 10 September 2015. Click here to read the full news story.

BREAKTHROUGH LUNG CANCER THERAPY?

Results from a clinical trial of the drug nivolumab have shown that it can double the life expectancy of some people with lung cancer.

Nivolumab works by inhibiting a protein called PD-L1, which normally switches off any part of the immune system that tries to attack cancerous cells.

The trial, conducted in Europe and the US, involved 582 people who had advanced lung cancer and who had already tried other treatments.

On average, people on standard therapy lived for another 9.4 months at this stage, but those taking Nivolumab lived for 12.2 months. While patients with tumors producing high levels of PD-1 lived for another 19.4 months.

Lead researcher Dr Luis Paz-Ares from the Hospital Universitario Doce de Octubre in Madrid, Spain, said, “[The results] mark a milestone in the development of new treatment options for lung cancer.

“Nivolumab is the first PD-1 inhibitor to show a significant improvement in overall survival in a phase III trial in non-squamous non-small cell lung cancer.”

From BBC News Online, 30 May 2015 Click here to read the full news story.

PREDICTING RESPONSE TO CHEMOTHERAPY

A new study has shown that the absence of the retinoblastoma tumor suppressor protein (pRB) can be used to determine if a lung cancer patient will respond positively to chemotherapy.

Scientists at Lawson Health Research Institute in London, UK discovered that patients who undergo chemotherapy and surgery experience significantly improved survival rates when their tumor is lacking the pRB.

The pRB protein is traditionally understood to help regulate cell division, preventing the growth of abnormal cells. However, recent studies have had conflicting results.

Dr Matthew Cecchin, a pathology resident at the London Health Sciences Centre (LHSC), wanted to see if there was a correlation between the small percentage of adenocarcinoma patients who do not have the protein and long-term survivors.

Under the leadership of Lawson’s Dr Fred Dick, Cecchin and a collaborative team of researchers performed a study on 91 lung cancer patients who underwent chemotherapy and surgery.

The study, which appears in Human Pathology, found pRB was not detected in 15% of patients. These patients experienced an improved survival rate of 92% at five years. This is in comparison to an average survival rate of 49% for those patients who expressed the protein.

From EurekAlert, 3 November 2015. Click here to read the full news story.

QUIT SMOKING, LIVE LONGER WITH LUNG CANCER

People with lung cancer live longer if they quit smoking around the time of their cancer diagnosis, a new study published in the Journal of Thoracic Oncology has found.

Researchers from Roswell Park Cancer Institute in Buffalo, USA looked at 250 lung cancer patients who were smokers and were referred to a program to help them stop smoking. Fifty had recently quit smoking, and 71 had quit smoking soon after being referred to the tobacco cessation program.

Those who quit smoking shortly before or after they learned they had lung cancer lived an average of 28 months. Those who continued to smoke lived an average of 18 months. Even patients with advanced lung cancer gained extra survival time if they quit smoking.

The researchers also found that patients who didn’t quit smoking but continued their attempts to quit may also live longer. However, death rates for those who quit and then started smoking again were similar to those who didn’t quit.

From Newsmax Health, 17 July 2015. Click here to read the full news story.
With the Lung Cancer Alliance celebrating its 20th anniversary this year, we take a look at some of its recent successes and the wide range of support it provides to people affected by lung cancer.

In the United States, over 200,000 people are told they have lung cancer every year. Not only does this affect the person who receives this news, it also greatly impacts on the lives of their family members and friends. This means in the country today there are millions of people who are living with the consequences of a lung cancer diagnosis.

Offering vital help to these people is Lung Cancer Alliance. It was established in 1995 to provide high-quality support, education and advocacy for those living with and at risk of lung cancer, and to advance research into the illness.

Twenty years on, Lung Cancer Alliance’s 21 members of staff continue this vital work from its headquarters in Washington DC. Their current overall vision is to triple the survival rate from lung cancer in the US by 2020.

Although this goal is certainly ambitious, the organization has achieved a lot in recent years and developed innovative programmes of work to turn this vision into reality. Kay Cofrancesco, Director of Marketing at Lung Cancer Alliance, says this includes, “Securing $102 million from Department of Defense for lung cancer research.

“We have also led the efforts to secure coverage and implementation of lung cancer screening for those at high risk throughout the US. Our Deserves to Die campaign, which calls on the general public to stop thinking that people with lung cancer somehow deserve it, has helped to change the vernacular surrounding lung cancer.

“And our most recent awareness campaign, How It Feels, has sought to capture what people may experience when faced with a diagnosis of lung cancer, either theirs or a loved one’s. Through the campaign, we turn clichéd expressions of the way people feel – getting hit by a train, being under the ground giving out from under you – into visuals that connect with our audience.”

In addition to this innovative work, Lung Cancer Alliance also provides a wide range of services to help improve the lives of people affected by lung cancer. These include:

**Lung Cancer HelpLine** – anyone can ring for free to ask any questions or chat about any concerns they have regarding their risk of developing lung cancer, what will happen following a lung cancer diagnosis and what the treatment of lung cancer will involve.

**LCA Unite mobile app** – an app for mobile devices that allows people to connect with others affected by lung cancer, anytime, anywhere.

**Lung cancer educational materials** – easy-to-understand materials to help lung cancer patients and their loved ones learn about treatment options, coping with symptoms, side effects and emotional aspects of the illness.

**GUIDES program** – this matches loved ones and caregivers of someone with cancer who is at the end-of-life or has died from lung cancer to other people who understand what they are going through. Volunteers provide information, support and resources.

**Support groups** – LCA tracks lung cancer support groups across the country and lets people know which is the nearest one to them.

**Clinical Trial Matching service** – a pre-screening and referral service that identifies clinical trial options. Navigators find available trials based on the patient’s diagnosis and treatment history.

Overall, the Lung Cancer Alliance has been a safe place for those affected by lung cancer for 20 years, and achieved many successes to improve the detection and treatment of the illness. We’re sure it will accomplish even more over the next 20 years, and continue to work together with other members of the GLCC to improve the outcomes and lives of people affected by lung cancer around the world.

“Our organization was one of the nine founding members of GLCC,” says Kay Cofrancesco. “Over the past 14 years, we’ve shared ideas and benefited from lessons learned in other countries. Also, by unifying our voice, GLCC members have added strength to our messages and helped more people know where to go to make a difference or for support.

“Our work together is paramount to creating long-lasting change. So thank you to everyone for all you’ve already done to help those who are living with or at risk from lung cancer. Let’s keep up the great work!”
LET’S TALK
STEFANIA VALLONE

IN OUR REGULAR SERIES OF QUESTION AND ANSWER ARTICLES, WE SPEAK TO STEFANIA VALLONE, SECRETARY OF WOMEN AGAINST LUNG CANCER IN EUROPE.

Q. When did you join Women Against Lung Cancer in Europe (WALCE)?
A. In 2007, shortly after the organisation was formed in Turin in September 2006.

Q. Why was your organization established?
A. WALCE was founded to increase women’s awareness of the increasing incidence and mortality of lung cancer in women over the past 40 years, and to stress their need to take care of their lungs in the same way as they do with their breasts. But since that time, the organization has started to develop educational and supportive activities for all lung cancer patients and their families.

Q. How many people are affected by lung cancer in Europe?
A. In Europe there are about 400,000 new cases of lung cancer every year, and about 340,000 deaths. The illness is particularly relevant to women right now because cancer death rates among European women in 2015 are expected to overtake those of breast cancer for the first time.

Q. In your opinion, are these people receiving the support and care they need?
A. In Italy (where WALCE is based), as in the rest of Europe, the situation in terms of lung cancer care and support remains quite heterogeneous. In Italy, the quality of care is not standard and not always guaranteed.

For these reasons, diagnoses are often made too late and access to new treatments is difficult. This generates a “health migration”, where people from one region go to another to try to obtain the best care.

Q. What care, support and services does WALCE provide?
A. A wide range of information for patients and caregivers about lung cancer related issues, including a lung cancer clinical trial database, from which patients can find the nearest hospital where new treatments are available as part of a trial. We also advocate on their behalf to make sure their rights are respected.

We help people access psychological support and share experiences and concerns. We also offer make-up courses to women receiving therapies, to help them regain their femininity, which may have been affected by changes to their body. And we give people the opportunity to take part in relaxation technique courses, natural cookery courses and mindfulness sessions.

Another area of WALCE’s work is prevention, so we deliver anti-tobacco campaigns in primary and high schools. And we produce awareness campaigns to increase people’s knowledge of lung cancer and decrease the stigma that surrounds the illness and lung cancer patients.

Q. Tell us about an inspirational person you’ve met whilst working at WALCE.
A. Denis, a lung cancer patient I met almost four years ago. He was just a nice guy who became one of my best friends. Almost six months ago he passed away; he was just 40, just as young as me, and he had struggled against this enemy for five years.

I will never forget his strength, dignity and sweetness whilst living with lung cancer. He fully lived life till the end. For everyone, but especially young people like Denis, I’ll continue to advocate for having more funds allocated to lung cancer so patients receive the best care and support.

Q. Why did your organization join the GLCC?
A. The voice of a single lung cancer patient association can be weak when it’s isolated. At any level, I strongly believe in cooperation and shared goals to get good results.

Q. Do you think GLCC members can benefit from each other?
A. In such a global group, there are differences in terms of knowledge and cultural backgrounds. But these differences are something we can all learn from. We can share different experiences and ways of working, outcomes, gaps and challenges so we all benefit.

And because the needs of lung cancer patients and the barriers they face are often universal, we can work with the same targets in mind, and hopefully reach them faster and save resources at the same time.

Q. Have you gained any knowledge from another GLCC member that has benefited your organization?
A. Yes, especially at the beginning of my time with WALCE. Working with more experienced people could be hard sometimes, but it also provided a good opportunity for me to get inspired and improve the work I do.

Q. Can you think of a media campaign by a GLCC member organization that you thought worked particularly well?
A. In general, I always look with great interest at all the educational and awareness campaigns produced by my GLCC colleagues. Over the years there have been a lot of very interesting ones. But I’d particularly like to mention the work of the Mexican group, Respirando Con Valor. I strongly admire their effort to reach people in such a huge country, and with very little support and poor access to treatments. They’re doing a great job!

Q. What message would you like to send to your fellow GLCC members?
A. I would like to thank them for their precious cooperation over the years. Every time I’ve needed their support I’ve received it. We are a global group, so we are different in some ways, but we work for a common goal: fighting against lung cancer and erasing the stigma of it. So let’s keep walking on together to reach that goal!
In 2015, 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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<td>Roy Castle Lung Cancer Foundation:</td>
<td><a href="http://www.roycastle.org">www.roycastle.org</a></td>
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<td>National Lung Cancer Forum for Nurses:</td>
<td><a href="http://www.nlcfn.org.uk">www.nlcfn.org.uk</a></td>
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<td>Lung Cancer Alliance:</td>
<td><a href="http://www.lungcanceralliance.org">www.lungcanceralliance.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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<td>Prevent Cancer Foundation:</td>
<td><a href="http://www.preventcancer.org">www.preventcancer.org</a></td>
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<td>Free to Breathe:</td>
<td><a href="http://www.freetobreathe.org">www.freetobreathe.org</a></td>
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