In 2001, nine organizations with an interest in lung cancer came together and formed the Global Lung Cancer Coalition. Today, the GLCC comprises of 31 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.

GLOBAL LUNG CANCER ATLAS LAUNCHED

The GLCC has launched a new interactive map that allows lung cancer patients, clinicians and policymakers to compare lung cancer statistics from around the world.

The Global Lung Cancer Atlas makes the latest published information about lung cancer impact and outcomes in different nations accessible in one place.

This offers the global lung cancer community a single statistical resource that they can use to compare countries, benchmark progress and campaign for change.

As well as featuring incidence, mortality and survival rates across the globe, the atlas also details whether a country operates a cancer plan or has implemented the World Health Organisation Framework Convention on Tobacco Control.
NEWS AROUND THE GLCC

LUNG CANCER AWARENESS MONTH 2014

In November 2014, many members of the GLCC used Lung Cancer Awareness Month to focus on lung cancer issues and lung health in their country.

Here, we look at a few of the highlights:

LungFoundation Australia
LungFoundation Australia launched a new initiative on 1 November that explores what extraordinary things can be done with Just One Breath. Focusing on positive health and wellbeing, the campaign’s aim is to inspire conversations about lung health.

Click here to find out more about Just One Breath.

Canadian Lung Association
The Canadian Lung Association launched Breathing as One, a fundraising campaign bringing patients, researchers and donors together to breathe new life into lung research. The campaign aims to break down the barriers that impede advances in the understanding, prevention and treatment of lung disease.

Click here to find out more about Breathing as One.

Irish Cancer Society
The Irish Cancer Society used Lung Cancer Awareness Month to call on the public to reduce their risk of being diagnosed with lung cancer, and to become more aware of the symptoms of the disease. This followed a report that ranked Irish women among the highest in Europe for lung cancer incidence and mortality.

See page 6 for ‘Biggest killer of women’ news article.

Roy Castle Lung Cancer Foundation
The Roy Castle Lung Cancer Foundation had its most successful Lung Cancer Awareness Month to date. As well as raising thousands of pounds for lung cancer research, it distributed almost 300 lung cancer information packs and raised awareness of lung cancer with the help of its 12-foot high MEGA Lungs.

JOURNALIST AWARD WINNER

The GLCC announced Bridget Huber as the overall winner of its 2014 Global Lung Cancer Journalist Award.

Selected from a shortlist of candidates who had won national GLCC awards in their own countries, American journalist Bridget won the award for her feature story Stigma of ‘smokers disease’ stifles fight against no.1 killer, lung cancer.

On receiving her award, a delighted Bridget said, ‘Thank you so much for this honor. Your recognition is doubly welcome, since this is a story that meant a great deal to me.’

Read our Q&A with Bridget on page 10.

Click here to read Bridget’s award-winning article.

ANNUAL MEMBERS MEETING 2015

The GLCC’s annual members meeting will coincide with the 16th World Conference On Lung Cancer, which takes place in Denver, USA, from 6–9 September 2015.

The GLCC will also be hosting a session at the conference between 2.15–3.45pm on Monday 7 September. Titled Advocacy in Action, it will be chaired by Maureen Rigney (USA) and Joan Schiller (USA) in the Colorado Convention Center and feature the following talks:

- Global Lung Cancer Atlas: How this can be used as a tool to advocate for change? – Sarah Winstone (UK)
- Bibliometric research on published lung cancer research: What are the implications for policy work? – Richard Sullivan (UK)
- The value of national lung cancer audit data: The United Kingdom experience – Jesme Fox (UK)
- Advocating for tobacco control: The Australian experience – Matthew Peters (Australia).

The GLCC will also host a stand at the Exhibition Center, which members are encouraged to visit.
Currently, less than 3% of cancer patients enrol in a clinical trial, and participation rates are even lower in lung cancer patients. Increased participation in clinical trials could potentially accelerate the pace of research and drug development, allowing patients to live longer and have a better quality of life.

The two organizations are now calling on innovators across the globe to enter their Clinical Trial Innovation Prize by submitting novel and creative ideas that will help overcome the barriers that prevent the accrual of cancer patients to clinical trials. The closing date for entrees is 6 May 2015 and the entrants with the best three ideas will be awarded a total of $30,000 USD in prizes.

Then, in July 2015, a Proof of Concept Prize will go live, which asks innovators to provide proof that their ideas have resulted in an increase in participation in cancer clinical trials. The winners of this competition will be awarded a total of $45,000 USD in prizes.

Lung Cancer Canada unveiled The Faces of Lung Cancer: Fighting Disease, Fighting Disparity report in November 2014.

It provides personal insights from patients and families about lung cancer, an illness that is estimated to touch more than half of Canadians in their lifetime. The report also addresses five key priorities based on research from Canada’s leading lung cancer specialists as well as the country’s patient community.

The key priorities are:

- The importance of screening
- Stigma
- The incredible toll on the Canadian population
- The status of current research
- Access to diagnosis and treatment

Lung Cancer Canada says the aim of the report is to raise awareness of those fighting lung cancer, and to help push forward a national dialogue on the state of this devastating disease in their country.

Lung cancer touches more than half of Canadians during their lifetime.
IRISH CHARITIES TAKE ON ‘BIG TOBACCO’

GLCC member the Irish Cancer Society and the Irish Heart Foundation are going head-to-head with the tobacco industry in response to misinformation it has spread about plain tobacco packaging.

This February, the charities launched a ‘truth drive’ by sending all 166 members of the Irish parliament a sample version of the planned ‘plain packs’ cigarette boxes and briefing materials. These materials contained the facts on how plain packaging has worked successfully in Australia, how it will not increase smuggling and how it does not interfere with intellectual property laws.

Kathleen O’Meara, Head of Advocacy and Communications at the Irish Cancer Society, said, ‘Cigarette companies have been spreading misinformation to our TDs [members of parliament] about plain packaging and threatening our sovereign government with legal action if Ireland introduces plain packs.

‘This is Big Tobacco at work. The deep pockets of global cigarette companies are being used in an attempt to derail this essential public health measure. We know that they have not only hired a number of large legal firms in Dublin, but that many PR companies have also been hired to bombard journalists and newsrooms in an attempt to get their misinformation published.

‘We believe a truth drive is needed in the face of the tobacco industry’s opposition to this critical piece of health legislation. While we cannot match the massive money being spent by Big Tobacco on this campaign, we are doing what we can to counter the misinformation being peddled by the tobacco companies.’

TRAINING THE TRainers

Pulmonale continued its efforts to reduce the number of lung cancer cases in Portugal by providing smoking prevention and cessation training to trainers at the national Employment and Professional Training Institute.

The vocational trainers were identified as key figures in the fight against lung cancer because of their regular contact with unemployed people and those of a low socioeconomic status, a group that has a high prevalence of smoking and lung cancer cases.

The training delivered by Pulmonale involved a number of group sessions which allowed participants to share ideas and personal stories and develop smoking prevention and cessation activities that they could use in their own course modules. Plus, the trainers also received online support following the completion of these sessions.

Pulmonale says the feedback it received from the trainers about the training was extremely positive. They now hope to replicate it across Portugal.
LUNG CANCER NUTRITIONAL CARE INFORMATION

In the UK, a new practical guide for lung cancer nutritional care, which includes a lung cancer nutritional care pathway, has been launched to assist the management of patients with lung cancer.

Endorsed by GLCC members the National Lung Cancer Forum for Nurses (NLCFN) and the Roy Castle Lung Cancer Foundation (RCLCF), the document aims to assist clinicians with assessing and monitoring the nutritional status of patients with lung cancer, in order to improve outcomes and patient experience.

In addition, to support the pack, NLCFN and RCLCF have also worked together to develop a nutrition starter information pack for lung cancer patients. It includes three leaflets covering practical tips for eating, using supplements and managing symptoms.

Click here to read the full news story.

KYOTO DECLARATION FOR LUNG CANCER TREATMENT

At the 55th annual meeting of the Japanese Lung Cancer Society, a declaration was approved regarding how lung cancer treatment should be provided in Japan in the future.

Developed by healthcare professionals, patients and members of lung cancer organizations, including GLCC member West Japan Oncology Group (WJOG), the Kyoto Declaration focuses on the need for doctors, medical staff, patients and the public to work together to improve the lives of people diagnosed with lung cancer.

At the annual meeting, this ambition was expressed through five statements that were read aloud by representatives of key stakeholders. These included Toshiyuki Sawa, who is a physician and a member of the GLCC, WJOG, JLCS and IASLC advocacy committee.

Tetuya Mitsudomi, the next president of JLCS, was the final speaker, who approved the following five statements with all members:

1. We realize the need for patient-centred care in the field of lung cancer.
2. We raise public awareness of lung cancer treatment by providing the correct information.
3. We collaborate with medical staff, nurses, pharmacists and social workers.
4. We propose our policies to the nation and the government.
5. We form a strong alliance with the enterprises, organizations and stakeholders involved with lung cancer treatment.

Click here to watch subtitled footage of the annual meeting.

WALCE NEW BOOKLET AND PARTNERSHIP

Women Against Lung Cancer Europe (WALCE) has developed with the Italian Association of Medical Oncology an English and Italian version of a booklet that aims to educate cancer patients about immune-oncology therapies.

The two organizations have also planned a series of meetings in Italian cities to improve physicians’ and nurses’ knowledge of immune-oncology therapies, which can have significant benefits for patients who have previously had few treatment options available to them.

In addition, WALCE has joined forces with the Bonnie Addario Lung Cancer Foundation and the Addario Lung Cancer Medical Institute to improve the lives of lung cancer patients worldwide. This will involve the three organizations and other partners working together on public relation exercises, marketing and promotional projects, patient educational programmes, patient services projects and clinical trial initiatives.

Click here to watch subtitled footage of the annual meeting.
**BIGGEST KILLER OF WOMEN**

Two recently published reports have identified that lung cancer has overtaken breast cancer as the biggest cancer killer of women in many areas of the world.

In Europe, a study led by Prof Carlo La Vecchia of the Faculty of Medicine at the University of Milan, which was published in the *Annals of Oncology*, predicts lung cancer death rates will outnumber breast cancer death rates among European women in 2015 for the first time.

The study reports that the predicted age-standardized death rate for lung cancer in 2015 will have increased by 9%, with lung cancer-related deaths estimated in 14.24 per 100,000 women. Death rates from breast cancer, meanwhile, are predicted to decline by 10.2% to an estimate of 14.22 deaths per 100,000.

In the US, a study led by American Cancer Society researcher Lindsey Torre, which was published in *CA: A Cancer Journal for Clinicians*, reported that lung cancer now kills more women than breast cancer in developed countries. Using data from 2012, it reveals that lung cancer killed 209,000 women in developed countries in that year, while 197,000 women died of breast cancer.

**CANCERS DOWN TO BAD LUCK?**

Good luck, rather than good genes, may be the key reason why some people are protected from certain cancers while others develop the disease, according to a new study.

Two-thirds of adult cancers, say researchers from the Johns Hopkins Kimmel Cancer Center in the United States, are caused by random mutation in the tissue cells during the ordinary process of stem cell division. In the other third, our genetic inheritance and lifestyles are the main factors.

The scientists have created a mathematical model which, they say, shows it is wrong to assume that there are such things as ‘good genes’ that may prevent us getting cancer even though we smoke, drink heavily and carry excessive weight.

**LUNG CANCER AND DEPRESSION**

A new study by researchers from Oxford and Edinburgh universities has revealed that as many as 75% of cancer patients do not receive effective treatment for clinical depression.

Published in *The Lancet Psychiatry*, the study analysed the data of more than 21,000 cancer patients in Scotland. It found that clinical depression tends to be more prevalent among cancer patients compared with the general population. Depression occurring in 6–13% of cancer patients, while the incidence only occurs in 2% of the general population.

Depression also appears to be more common in patients with lung cancer, affecting about 13% of lung cancer patients involved in the study, followed by those diagnosed with gynaecological cancer (10.9%), breast cancer (9.3%), colorectal cancer (7%) and genitourinary cancer (5.6%).

**LUNG CANCER LYING DORMANT**

Lung cancers in ex-smokers can lie dormant for as long as 20 years before they begin to grow into a life-threatening tumor, a study has reported in the *journal Science*.

Scientists discovered that the original mutations in lung cells caused by inhaling cigarette smoke can date back many years before additional mutations cause them to become aggressive cancer cells.

The researchers carried out a genetic analysis of the tumor cells from seven lung cancer patients and found a surprising variation within each tumor in terms of the DNA mutations that triggered the disease.

The research, which was jointly funded by Cancer Research UK and the Rosetrees Trust, highlights the need for better ways to detect the disease earlier. Two-thirds of patients have advanced forms of the disease at diagnosis, which is when treatments are less likely to be successful.
**PRIOR CANCER SHOULDN’T PREVENT CLINICAL TRIAL INCLUSION**

The common practice of excluding patients with a prior cancer diagnosis from lung cancer clinical trials may not be justified, according to a study by researchers from the University of Texas Southwestern Medical Center.

Appearing in the *Journal of the National Cancer Institute*, the study reports that having previously had cancer does not impact on the clinical outcomes of people with advanced lung cancer, and that these patients should be considered for inclusion in clinical trials seeking new therapies.

‘When it comes to clinical trial eligibility, a history of prior cancer should not count against you,’ said senior author Dr David Gerber, Associate Professor of Internal Medicine in the Division of Hematology and Oncology in the Harold C Simmons Comprehensive Cancer Center.

‘For patients with advanced lung cancer, previous cancer does not adversely affect survival, regardless of the type, stage, or timing of the prior cancer.’

Currently, less than 3% of adults with cancer in the US participate in clinical trials.

*From Medical XPress, 9 February 2015. Click here to read the full news story.*

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**BLINDNESS THREAT PROVES EFFECTIVE SMOKING DETERRENT**

The threat of blindness deters smokers more than other health warnings, according to academic findings.

Researchers at the British Thoracic Society’s winter meeting said there was low awareness of the risk of blindness from smoking, but it had a much higher ‘detering impact’.

Overall, it was found the longer people were exposed to the graphic health warnings on cigarette packets, the more their sensitivity and engagement was reduced.

The study, led by academic Culadeeban Ratneswaran from Guy’s and St Thomas’ Hospital, London, involved 266 participants, with 163 from London, including 56 smokers, and 103 from Singapore, including 55 smokers.

The UK sample had a statistically higher awareness of how smoking increases the risk of heart disease, mouth and throat cancer and lung cancer, but significantly lower awareness of the effect of smoking on the risk of blindness.

Singapore has used graphic health warnings for five years longer than the UK and smokers and non-smokers in the Singapore sample reported lower levels of disgust when viewing the warnings compared to the London sample.

*From Optician, 5 December 2014. Click here to read the full news story.*

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**COUGH CAMPAIGN SUCCESS**

A campaign in the UK urging people with a persistent cough to visit their doctor led to a surge of lung cancers diagnosed at an early enough stage for patients to receive surgery which could be curative.

According to analysis of the campaign, doctors made more than 3,000 extra referrals of people with suspected lung cancer. This is an increase of more than 30% in referrals during the months (May to July 2012) surrounding the Be Clear on Cancer campaign, compared with the same three-month period the year before.

Most importantly, in the months surrounding the campaign around 700 extra patients were diagnosed with lung cancer – many at an early stage – and nearly 300 more patients received surgery.

While a survey of 1,100 people conducted after the campaign showed that, when prompted, 33% were aware that a cough lasting more than three weeks was a definite warning sign of lung cancer, compared with only 18% before the campaign.

Experts believe that this kind of awareness campaign can lead to earlier diagnoses that give patients a better chance of successful surgery, follow-up treatment and prolonged survival.

*From Cancer Research UK, 3 December 2014. Click here to read the full news story.*
CELEBRATING ITS 25TH ANNIVERSARY THIS YEAR, WE TAKE A LOOK AT THE HISTORY OF THE ROY CASTLE LUNG CANCER FOUNDATION AND ITS PLANS FOR THE FUTURE.

The UK’s only lung cancer charity was established in 1990 by Professor Raymund Donnelly, a cardiothoracic surgeon who was concerned by the high rate of lung cancer cases and the fundamental lack of research into the disease.

Professor Donnelly wanted to create a charity dedicated to the study of all aspects of lung cancer, and which had clear objectives regarding research, patient support and smoking prevention; these remain virtually unaltered to this day.

An inspiring celebrity endorsement
Initially known as the Lung Cancer Fund, the charity made rapid progress with support from patients and the local media in Liverpool. This led to enough money being raised for the charity to fund research at the University of Liverpool and appoint the first ever lung cancer support nurse.

A year later Professor Donnelly carried out the first keyhole surgery to remove a lung cancer tumor, gaining international publicity and further boosting the charity’s profile.
The charity then approached the popular musician, actor and TV personality Roy Castle, who had been diagnosed with lung cancer, to support its plans for an international research centre in Liverpool. His incredible response helped to catapult the charity to a new level.

Roy Castle spent his final months campaigning bravely on the charity’s behalf and undertook a nationwide Tour of Hope which raised more than £1 million in three days. After his death, the trustees agreed to Professor Donnelly’s idea to rebrand the charity as the Roy Castle Lung Cancer Foundation.

Shortly afterwards, a nationwide patient information and support service was launched; it is now the largest supplier of lung cancer information to the National Health Service in England, Scotland, Wales and Northern Ireland and runs a network of more than 50 patient support groups across the UK. It is based at the charity’s Glasgow office, which is also the secretariat for the Global Lung Cancer Coalition.

Series of important achievements
Construction of the Roy Castle International Lung Cancer Research Centre was completed in 1997, prompting the charity to take its message around the world. This included visits to four continents and many major cities to meet with doctors, scientists, media and politicians, including the late Nelson Mandela.

The charity also persuaded Liverpool City Council to appoint the first ever smoking prevention officer and form a tobacco abuse working party. This has helped thousands of local people to quit smoking in the past 20 years.

The Roy Castle Lung Cancer Foundation also played a pivotal role in campaigning for a smoking ban in public places in the UK, with one of its trustees introducing a parliamentary bill that eventually led to government legislation.

Today, it continues to invest in research, with more than £1 million per year spent on improving the early detection of lung cancer and enhancing the experience of lung cancer patients.

For 15 years it has also worked hard to secure a breakthrough for lung cancer screening, an issue that’s now receiving much interest around the world, clearly demonstrating the charity’s position at the forefront of lung cancer campaigning.

Committed to beating lung cancer
Paula Chadwick, chief executive of the Roy Castle Lung Cancer Foundation, says, ‘This is our 25th anniversary year, and while we have so much to look back on with enormous pride, our focus is very much on looking ahead to the next 25 years. Lung cancer remains the UK’s biggest cancer killer, and the challenge for us is to save more lives and beat this terrible disease.

‘The way to do this is by improving early detection methods to give patients a greater chance of survival. This forms the basis of much of our ongoing lung cancer research work. We are also working hard on finding ways to improve the experience of lung cancer patients and encourage new treatment options to be made available.

‘Public awareness campaigns are crucial to achieving this goal, and we have a vital role to play in helping potential sufferers and primary care providers to improve their understanding of the common symptoms and seek further examination where necessary.

‘We also await with great anticipation the outcome of European lung cancer screening trials, which, if successful, could herald a new dawn for lung cancer detection and survival rates.

‘Over the next 25 years, we are wholly committed to making real inroads into beating lung cancer once and for all. Our vision is a world where no one dies of lung cancer and we will be able to shut the doors of our charity.’

Our vision is a world where no one dies of lung cancer and we will be able to shut the doors of our charity.

Paula Chadwick, chief executive of the Roy Castle Lung Cancer Foundation

For further information about the Roy Castle Lung Cancer Foundation and its work, please visit www.roycastle.org
IN OUR REGULAR SERIES OF QUESTION AND ANSWER ARTICLES, WE SPEAK TO AMERICAN JOURNALIST BRIDGET HUBER, WINNER OF THE GLCC’S 2014 GLOBAL LUNG CANCER JOURNALIST AWARD.

Q. You won the GLCC’s Global Lung Cancer Journalist Award for your article Stigma of ‘smokers disease’ stifles fight against no.1 killer, lung cancer. Who or what inspired you to write the article?

A. My fantastic editor at FairWarning, Myron Levin, suggested I look into lung cancer. A man whose wife was sick with the illness brought to his attention the inequalities that surround the disease.

Myron was especially stuck by how much less the Defense Department in the US spends on lung cancer research as opposed to other cancers, such as breast cancer, especially since way more men are in the armed services and cigarettes were once part of a soldier’s rations!
Q. What has been the reaction to your article, apart from you receiving the GLCC award?
A. It got a very good response. I heard from people who have lung cancer and those who have lost loved ones to it. They were happy to see the issues of stigma and research funding addressed.

Dr Len Lichtenfield, the American Cancer Society’s chief medical officer, wrote a thoughtful blog post responding to some of the issues I raised in the story, which I was happy to see, especially since some of the people that I’d interviewed expressed frustration about that organization’s attitude towards lung cancer.

Click here to read Dr Litchenfield’s blog post.

Q. How did it feel to win the Global Lung Cancer Journalist Award for 2014?
A. It was wonderful and humbling! Of course, it’s always an honor to be recognized, but this story meant a great deal to me, making the award even more meaningful.

I was deeply touched and humbled by my conversations with people who are living with lung cancer, and by those who have lost loved ones to this terrible disease. I was deeply touched by the stories people so generously shared with me.

I was also impressed by the tenacity and commitment of the advocates and researchers who are working to find new treatments and push for political and cultural change.

I am deeply grateful to those who shared their stories with me, even though I know it was painful to do so, and to the researchers and advocates who patiently explained their work to me and helped me navigate this terrain.

Q. What do you think needs to happen to change the public’s perception of lung cancer?
A. It seems to me that eliminating stigma would go a long way. The people I interviewed for this story articulated the double standard that applies in the way we think about people with lung cancer.

When we hear someone has lung cancer, many people automatically wonder if that person smoked. But many conditions and cancers can be caused, partially or fully, by our choices around what we eat and drink, how much we exercise, whether we stay out of the sun, etc. Yet when we hear that someone has a heart attack, we tend to respond with compassion; we don’t blame the victim by asking whether that person went to the gym enough.

So, I think we need to get past the stigma, which affects former smokers and never-smokers alike. The other thing that I think needs to be recognized is that tobacco companies spent decades and millions of dollars countering the science about cigarettes’ dangers, making more addictive products, hooking young people and finding ways to sell them to consumers.

Their evils are widely recognized, yet we still blame smokers and former smokers for falling prey to the tobacco companies. That doesn’t seem fair.

Q. What needs to happen to get politicians to commit more funds to lung cancer research?
A. I don’t really know, but it does seem like the more lung cancer advocates can work together and tell their stories, the more the public and politicians will have to pay attention.

As I started learning about the subject, I was shocked to see how many people die of lung cancer and how little survival rates have improved over the decades. I think communicating those facts is crucially important.

Q. Do you have any plans to write more articles about lung cancer and the need for greater research?
A. I would love to! I’m very open to ideas on how to move this story forward and invite readers of Unity to contact me at bridgethuber@gmail.com or on Twitter @bridgethuber with their suggestions.

NATIONAL GLCC JOURNALISM AWARD WINNERS

Robert Peston (UK)
Dawn O’Shea (Ireland)
Bridget Huber (US – winner)
Charlotte Huff (US – runner-up)
Wanda de Kanter and Pauline Dekker (Netherlands)
Débora Carvalho and Paula Rebelo (Portugal)
Editors of TargatoCn (Italy)
Nada Amr (Egypt)
### MEMBERS OF THE GLCC

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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>
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<td><a href="http://www.preventcancer.org">www.preventcancer.org</a></td>
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<td>United States</td>
<td>Free to Breathe</td>
<td><a href="http://www.freetobreathe.org">www.freetobreathe.org</a></td>
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- AstraZeneca, Boehringer Ingelheim, Bristol Myers Squibb, Eli Lilly, GlaxoSmithKline, Novartis, Pfizer, Roche.

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