In 2001, nine organizations with an interest in lung cancer came together and formed the Global Lung Cancer Coalition. Today, the GLCC comprises of 35 non-government patient organizations from around the world.

Our aim is to increase awareness of lung cancer issues, change perceptions of lung cancer, help people with lung cancer access the information and support they need, and push governments and legislative bodies to improve treatment and care.

Already, we have achieved a lot. But we also know that much more must be done to improve the outcomes and lives of people affected by lung cancer – something we are determined to do.

In early July, we published a study in The Journal of Thoracic Oncology that revealed the lack of lung cancer research taking place around the world in comparison to other cancers.

Titled The state of lung cancer research: A global analysis, the study showed that despite lung cancer being responsible for more deaths than any other cancer, it was the subject of just 5.6% of all global cancer research in 2013.

In addition, the study also revealed:

- Research into lung cancer has increased by just 1.2% since 2004.
- The relative commitment to lung cancer research has actually fallen in most countries over the past 10 years.
- 24 countries are responsible for more than 95% of global lung cancer research output.
- The majority of lung cancer research (53%) focuses on medicines, genetics and biomarkers.
- Despite most lung cancers having a poor survival rate, just 1% of research looks at understanding quality of life issues and improving palliative and supportive care.
- Late presentation and diagnosis of the disease are persistent issues that affect the chances of curative treatment being offered, but just 1.8% of total lung cancer research output is focused on screening and 4.4% on diagnostics.

Continues on page 2
**GLCC study reveals research scandal**

Continued from page 1

Dr Matthew Peters, chair of the GLCC, said: “The study clearly shows that, in terms of research commitment, lung cancer is very much the underprivileged poor cousin. It is a simple matter of equity – an intolerable worldwide scandal that a ‘non-sexy’ cancer is so badly neglected and that major research funding agencies have been slow in addressing this.”

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**LUNG CANCER JOURNALISM AWARDS**

Over the past 12 months, GLCC members from around the world have awarded 2015 Lung Cancer Journalism Awards to people who have helped raise awareness of lung cancer and issues that surround the illness.

- **Portugal**
  - Pulmonary学前 presented an award to journalist Carla Marina Mendes for an article about lung cancer and women, which was published in Destak, the first free daily newspaper in Portugal.

- **Russia**
  - Equal Right to Life nominated T了一nna Kosoglotova, a medical journalist, for her work covering a wide range of issues relating to lung cancer.

- **Japan**
  - Cancer Net Japan recognized the work of Kazuo Hesegawa, who has stage IV lung cancer. Kazuo, who is a television director, has formed a support group called One-Step, raised awareness of lung cancer issues and is currently making a documentary about his life with cancer.

- **Sweden**
  - Stödet gave its 2015 award to Susanne Hobohm, who was diagnosed with lung cancer in 2012. Susanne, a former editor, editorial writer, columnist, teacher in journalism, producer and reporter, has worked extensively with television, newspapers and magazines in Sweden to raise awareness of lung cancer.

- **Ireland**
  - The Irish Cancer Society presented an award to Irish Daily Star journalist Catherine Halloran for an article which highlighted that the lung cancer rate for women in Ireland is higher than in other European countries.

- **Netherlands**
  - Longkanker Nederlands awarded its Lung Cancer Journalism Award 2015 to Sandor de Hosson, a doctor of pulmonology at the Vrije Universiteit Medisch Centrum Amsterdam. Sander specialises in lung cancer and palliative care and wrote a moving article about a young man dying of lung cancer who he cared for.

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**IRISH CANCER SOCIETY SURVEY**

Research commissioned by the Irish Cancer Society has cast some light on why the majority of lung cancer cases in Ireland continue to be diagnosed at a late stage.

Following a survey of over 1,000 people, it was revealed that:

- **Just over a half of adults questioned were unable to identify lung cancer as the leading cancer killer.**
- **A third of people with three or more symptoms of lung cancer were unconcerned about being diagnosed with the illness.**
- **76% said they’d never spoken to their doctor or a pharmacist about lung health.**
- **54% felt there were obstacles preventing them from talking to a doctor about lung health, including fear (22%), expense (17%), not a serious enough issue (19%) and 22% of all adults spoken to and 32% of smokers surveyed said they would not go to their doctor because they feared what they would be told.**

To help increase early diagnoses of lung cancer in Ireland, the Irish Cancer Society has launched an Online Lung Health Checker. It is based on an online tool developed by fellow GLCC member Lung Foundation Australia.

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**GLCC NOMINATED FOR TOP AWARD**

We’re delighted that the GLCC was shortlisted in the Excellence in Healthcare Partnerships and Collaboration category at the 2016 Communiqué Awards.

The Communiqué Awards programme is specifically designed to recognise and commend excellence and best practice in local, European and international healthcare communications. In particular, the GLCC was recognised for the success of its lung cancer e-Atlas and its activities to highlight the need for more lung cancer research to take place around the world.

The winners of the awards were announced at a ceremony in London on 7 July, and while we didn’t win the top award in our category, we still feel very proud about being a finalist and what the GLCC has achieved over recent years. Thanks to the dedication and energy of all of the members of the GLCC, we really have taken steps forward in the fight against lung cancer.

We’d also like to send our congratulations to Saroott and the International Diabetes Federation, who won our category for their Kids and Diabetes in Schools pilot program in India and Brazil.

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**REFRESH OF GLCC WEBSITE**

Work has already begun to update and refresh the look and content of the GLCC website.

The aim of the update is to make it more user friendly and improve the way the work of the GLCC and its members is showcased.

The new website is set to be launched before the end of the year. Look out for updates in Unity and in your inbox.

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**EXPORT DATA FROM E-ATLAS**

The GLCC’s e-Atlas, which is available here, now features a function that gives everyone the opportunity to transfer data into graphs and charts for use in presentations and documents.

The global interactive map brings together the latest published information about lung cancer’s impact in different countries and allows you to easily compare these statistics.

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**LONGKANKER NEDERLAND IS HERE**

Netherlands GLCC member Longkanker Informatiecentrum became Longkanker Nederlands on 1 April 2016.

As well a launching a new website at longkankernederlands.nl the organization has appointed a new director in Marlene de Rigt. She has extensive experience of the healthcare sector, having worked in a range of positions at healthcare providers and industry associations.
NEW SUPPORT LINE LAUNCHED

Free to Breathe launched a free telephone support line in April this year to help patients and caregivers in the US face the challenges of lung cancer.

The support line came about after patients, caregivers and survivors expressed a need for easy access to information about a wide range of lung cancer topics. This includes diagnosis and treatment, molecular testing, second opinions, cancer centers of excellence, clinical trials, palliative care and caregiver support.

The Free to Breathe Support Line will also connect callers with helpful resources such as support groups, organizations that can provide assistance with financial issues, smoking cessation programs, legal services and local services that can help with practical and emotional issues.

Cheryl Petersen, the Free to Breathe program director behind the support line, said, "Speaking to a ‘live’ person can help reassure patients and caregivers that they are not alone in their fight against lung cancer."

"Unfortunately, many facing lung cancer lack the opportunity to talk to someone who understands. We are proud to be supporting patients with lung cancer and their caregivers with this new, free service."

The Free to Breathe Support Line is available on 1.844.835.4325, Monday to Friday, 8am to 4pm, Central Time.

LUNG FOUNDATION AUSTRALIA LAUNCHES PATIENT PATHWAY

Lung Foundation Australia has launched a Lung Cancer Patient Pathway (LCPP) to help patients understand their diagnosis and proposed treatment plan.

Ideally provided to people at diagnosis, the pathway features two main components:

- A visual representation (stepping stones) of the steps generally involved in a lung cancer journey
- A lung cancer profile for clinical staff or a patient to use to record information about the patient’s personal situation.

The LCPP is available as a printed or online resource from Lung Foundation Australia's website and will be promoted and distributed to healthcare professionals who support people affected by lung cancer.

OLYMPIC STAR FRONTS LUNG INITIATIVE

Lung Foundation Australia also announced in June that Cathy Freeman, the Olympic 400-metre gold medalist, had become the national ambassador for their Just One Breath initiative.

As part of her role, Cathy is fronting a series of video stories of other Australians living with a lung disease, and promoting early diagnosis through Lung Foundation Australia’s Lung Health Checklist.

"I’m proud to be working with Lung Foundation Australia to put a face to lung disease in Australia," said Cathy. "By sharing my own story, I hope to encourage Australians to start talking about their own lung health."

SHARING CANCER STORIES

ALCASE of Italy and Deutsche Krebsgesellschaft (German Cancer Society) are both bringing together cancer patients, survivors and caregivers to share experiences and support each other.

Following the success of their first national meeting, ALCASE is holding its second event for lung cancer patients and families in Milan on 24-25 September 2016. To find out more, visit the organization’s website at alcase.it

Meanwhile, Deutsche Krebsgesellschaft held its second German Cancer Survivors Day at Berlin Hauptbahnof, Berlin’s main station, on 1 June. It included 18 cancer survivors sharing their stories on a large stage at the station.

NEW AWARENESS CAMPAIGNS

Two GLCC members, Lung Cancer Canada and Mexico’s Respirando con Valor, have recently been hard at work developing new awareness campaigns.

In February, Lung Cancer Canada launched its The Hard Facts graphic, which brings to life the worrying prevalence of lung cancer in Canada.

And over the past few months, Respirando con Valor has created posters about how people can cope with common side effects of chemotherapy and how stopping smoking can benefit a person over time.

DEVELOPING LUNG CANCER SUPPORT GROUPS IN THE US

The Bristol-Myers Squibb Foundation's Bridging Cancer Care initiative has provided a grant to the US’s Lung Cancer Alliance to support its National Lung Cancer Support Group Network.

LCA’s Network connects existing and new lung cancer support groups with local partners so group facilitators can access training and guidance on how to establish and maintain a support group for lung cancer survivors.

Although an estimated 224,000 people will be diagnosed with lung cancer in the US in 2016, there are fewer than 100 lung cancer support groups available. Already, the funding from the Bristol-Myers Squibb Foundation is helping LCA work with two existing groups in Nashville, Tennessee, and Durham, North Carolina.

In addition, five new lung cancer support groups will be established in West Virginia, South Carolina, Georgia and Mississippi. And the LCA will partner with local hospitals and oncologists to help raise awareness about the support groups among lung cancer survivors.

QUALITY OF LIFE WHITE PAPER

CancerCare from the US released a new white paper in March that revealed quality of life concerns are more important to lung cancer patients than symptom management.

Compiled following discussions with lung cancer advocacy organizations and key opinion providers, the white paper, which is titled Improving the quality of life for lung cancer patients, offers the following recommendations:

- Quality of life (QOL) or patient reported outcome (PRO) factors should be as important as survival when determining individual treatments and overall management of lung cancer patients
- QOL and PRO factors, such as nutrition and exercise, should be incorporated into individual lung cancer treatment plans at diagnosis, and followed throughout the course of the disease.
- Social media provides a powerful venue through which the importance of QOL and PRO factors can be highlighted to lung cancer patients and caregivers.

Commenting on the white paper, Win Boerckel, CancerCare’s National Lung Cancer Program Coordinator, said, “It quickly became apparent throughout our discussions that there needs to be a robust call to action for both the lung cancer advocacy and healthcare provider communities to unite in a movement to bring about the integration of dietary and exercise interventions in the overall therapeutic effort in the treatment of all lung cancer patients.”
MIDDLE AGE AND ADVANCED LUNG CANCER

Patients aged 50 to 64 are more likely to be diagnosed with late stage lung cancer than older patients aged 65 to 69, according to new data presented at the Cancer Outcomes and Data Conference in Manchester, England.

Researchers examined the records of around 34,000 lung cancer patients in England in 2013 to explore the association of early and late stage lung cancer and age.

Previous research has shown that older patients may be diagnosed with certain cancers such as bladder and lung at an earlier stage compared to younger patients, but this is the first time this relationship has been explored using lung cancer data at a national level.

From Cancer Research UK website, 14 June 2016.
Click here to read the full news story.

NEW SCREENING RECOMMENDATION

The Canadian Task Force on Preventive Health Care has published new screening guidelines for adults aged 55 to 74 who are at a high risk of lung cancer.

They recommend that current or former smokers (quit in the past 15 years) from this age group who have a 30-packs-a-year history should be screened three times a year using a low-dose CT scan.

This guideline incorporates new evidence, including results from a large randomized controlled trial comparing low-dose CT scans with chest X-rays. The Task Force also says the guideline considers the benefits of early detection against the harms of over diagnosis and invasive follow-up testing.

From Canadian Medical Association Journal, 5 April 2016.
Click here to read further information about the guidelines.

SURGERY FOR OLDER LUNG CANCER PATIENTS

Older lung cancer patients are surviving longer when they have lung cancer surgery, a new study suggests.

In the study, which was published online in The Annals of Thoracic Surgery, researchers examined data from tens of thousands of patients aged 65 and older who had lung cancer surgery in the United States between 2002 and 2012. Median survival after surgery for early stage lung cancer was 6.7 years – nearly two years longer than the benchmark five-year survival rate.

The analysis also showed that five-year survival rates for certain older patients with advanced lung cancer who had surgery were 30% for stage 3 cancer and 27 percent for stage 4 cancer.

From WebMD, 5 May 2016.
Click here to read the full news story.

MONITORING APP BOOSTS SURVIVAL

A web-based app has been shown to improve the survival of patients with advanced lung cancer in a phase III trial.

The Moovcare app functions as a remote monitoring device and is used to report signs and symptoms that a lung cancer patient may be heading for a relapse or complication. Patients or their carers can use it to report clinical symptoms over time, with the information shared with their physician.

According to the team behind the app, the median overall survival of patients who used the app was 19 months, compared to just 12 for those who received standard follow-up care. Users of the app, which can be used with mobile devices, also had higher quality of life scores.

After a year, three quarters of the Moovcare group were still alive, compared to around half of patients given standard follow-up. The results are consistent with earlier trials using telehealth approaches, said the researchers, but the trial is the first to show a significant survival benefit for an app-based approach.

From PMLiVE, 8 June 2016.
Click here to read the full news story.
IN FOCUS
THE ISRAEL LUNG CANCER FOUNDATION

INSPIRED BY HER OWN PERSONAL EXPERIENCE OF LUNG CANCER,
DR SHANI SHILO IS DETERMINED TO RAISE AWARENESS OF THE ILLNESS IN ISRAEL AND HELP PATIENTS AND CARERS RECEIVE THE CARE THEY NEED.

In Israel approximately 2,279 people are diagnosed with lung cancer every year and 1,761 people die from the illness. As Dr Shani Shilo discovered when her husband, a never smoker, was diagnosed with stage IV lung cancer at the age of 43, many people don’t receive the specialist lung cancer information and support they need at diagnosis, during treatment, and beyond it.

In particular, Dr Shilo, a dentist from the city of Rehovot, became aware that there was no online community for people affected by lung cancer where they could learn from each other share, stories and offer support. A resource she felt would have greatly benefited herself and her husband, Elad, who is still alive five years after his diagnosis.

Inspired by her own struggles, Dr Shilo decided she wanted to set up an organization that would make a difference to the lives of lung cancer patients and their families in Israel. This led to her working with Professor Nir Peled, a lung cancer oncologist. Together, they identified what help was needed and how they could best raise awareness of the issues which surround lung cancer. Then, in April 2014, they launched The Israel Lung Cancer Foundation, the first organization in Israel specifically for people affected by lung cancer.

Improving people’s lives
Today, the Israel Lung Cancer Foundation is going from strength to strength, thanks to the tremendous efforts of the eight volunteers who run it. It provides vital information and support in Hebrew through its website and Facebook page. This includes forums where people can access professional support and talk with other people affected by lung cancer about how they’re feeling.

The organization also helps patients and caregivers to speak to each other over the phone; it has created videos and information graphics, promoted patient stories and advertised itself in newspapers to raise awareness of lung cancer and the help the foundation offers; and it has attended ministry of health meetings, which has led to new drugs becoming available for people diagnosed with lung cancer.

Dr Shilo says she’s very proud of what has been achieved so far but that she also has her sights firmly set on the future: “Over the next year or so, our priorities are holding an annual conference for patients and carers and professionals, starting up support groups and establishing lung cancer screening for heavy smokers in Israel.

“Further ahead, over the next five years, the organization would like lung cancer support groups to be available across the whole of Israel. We’d also like a task force to be in place that aims to improve the quality of life of patients and carers. And we’d like to open our own official headquarters and a rehabilitation center for patients with metastatic lung cancer.”

Learn from each other
Dr Shilo also adds that in the future she hopes The Israel Lung Cancer Foundation will become a more active member of the GLCC and work with other lung cancer organizations from around the world to learn and share knowledge.

“It’s important we join forces because lung cancer does not discriminate between nations. The problems and issues people face are the same around the world. But as members of the GLCC, we can learn from each other and make a difference to these people’s lives.

“We can get ideas for activities and campaigns. We can share printed information for patients and carers and data about lung cancer. We can also discuss lung cancer issues and promote the need for more research to take place across the globe.

“Even though I haven’t attended a GLCC meeting yet, I’ve already visited the websites of other members and been inspired. I’ve learnt about their activities and got lots of ideas about what we should feature on the website of The Israel Lung Cancer Foundation. That’s been really helpful for a young organization like us.”

For further information about The Israel Lung Cancer Foundation and its work, please visit www.ilcf.org.il
You can also find out more and watch videos produced by the organization on its Facebook page.
And you can contact Dr Shilo direct at shani@ilcf.org.il

“...It’s important we join forces because lung cancer does not discriminate between nations.”

Dr Shani Shilo, Chief Executive and co-founder of The Israel Lung Cancer Foundation

Professor Nir Peled
**LET’S TALK**  
**DR GIANFRANCO BUCCHERI**

**IN OUR REGULAR SERIES OF QUESTION AND ANSWER ARTICLES, WE SPEAK TO DR GIANFRANCO BUCCHERI, THE FOUNDER AND MEDICAL DIRECTOR OF ALCASE ITALIA.**

**Q.** When did you establish ALCASE Italia?  
**A.** In 1998. At the time it was the first organization for people affected by lung cancer in Italy, and one of only three such organizations in the world.

**Q.** What is your professional background?  
**A.** I studied medicine and surgery at the University of Pavia, in the Lombardy region of Italy. Following graduation, I began to specialize in respiratory diseases. This led to me establishing a working group with other pulmonologists in 1982 which is dedicated to the study and treatment of lung cancer. Today, this is called ALCARE, which plans clinical trials and interprets their results. I’m the scientific director for the group.

I also studied at the Mayo Clinic in Rochester, Minnesota, in the USA, and at the Royal Brompton hospital in London. And I’ve spoken at dozens of medical conferences and training courses, and written over 300 published pieces of original research, review articles and other scientific communications. Before becoming the medical director of ALCASE Italia, I was the medical consultant at S.Croce e Carle hospital in the city of Cuneo, in northern Italy.

**Q.** Where is the headquarters of ALCASE Italia?  
**A.** It’s in the town of Boves, which is in the province of Cuneo. Boves is located around 80km south of Turin and close to the border with France.

**Q.** How many people work for the organization?  
**A.** We only have three full-time members of staff.

**Q.** How many people are affected by lung cancer in Italy?  
**A.** The latest estimate is that there are 38,000 new cases of lung cancer in Italy every year.

**Q.** In your opinion, are these people receiving the support and care they need?  
**A.** On average, they receive an acceptable level of medical care, but there are big quality differences between hospitals and specialized medical centers in Italy.

In particular, the care provided in the south is largely under the average. Much work has to be done to improve the quality of medical care in southern regions.

We also believe the psychological care offered to people affected by lung cancer in all areas of Italy is inadequate.

**Q.** What care, support and services does ALCASE Italia provide?  
**A.** We provide a wide range of information and medical advice about lung cancer through our website. One of our most successful areas is our Ask the Expert service. This allows any visitors to the website to post a query to our lung cancer experts for free.

We also advocate on behalf of lung cancer patients and their families, to help make sure they receive the care and support they need. This includes our vital work as part of the GLCC.

And we share information about the clinical trials being carried out by ALCARE, and it’s work with other researchers.

**Q.** What difference does ALCASE Italia make to the lives of people affected by lung cancer?  
**A.** They become informed about the best medical centers in Italy, the most experienced doctors, the international guidelines for treatment and any new discoveries that could improve the treatment and quality of life of people diagnosed with lung cancer.

Furthermore, we provide specialized medical support by replying online to specific questions posed by patients and caregivers. And our medical experts can provide a second opinion to people who get in touch.

**Q.** Does your organization have any current lung cancer media campaigns?  
**A.** Yes. We are campaigning for the introduction of a national program to provide free low-dose CT screening to adults who are at risk of lung cancer.

**Q.** What are your organization’s main plans for the next five years?  
**A.** To increase the number of people who access our information. We’re also determined to win our campaign to introduce low-dose CT scans for people at risk of lung cancer.

**Q.** What is your organization’s ultimate ambition?  
**A.** To be known by all of the lung cancer patients in Italy, and all of their families, as a respected and recognized source of quality information about the illness.

**Q.** Tell us about an inspirational person you’ve met whilst working in your current position?  
**A.** Peggy Barger, the founder of ALCASE in the USA (now the Lung Cancer Alliance) and the people she was working with in the late 1990s. They were at the forefront of forging links between people around the world who want to improve the lives of people affected by lung cancer.

What Peggy achieved in the USA really helped to inspire the work of ALCASE Italia.

**Q.** What message would you like to send to your fellow GLCC members?  
**A.** I’d encourage each member organization to create a presence, or expand their current presence, on social networks, especially on Facebook and Twitter. These are excellent ways to share important information around the world, as soon as it becomes available.

**Q.** Finally, what do you like to do in your spare time?  
**A.** I enjoy alpinism, which is a type of mountaineering that involves fast climbs using few camps and little equipment. I also like to go backcountry (off-piste) skiing, cycle, run, read and travel.
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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