



GLCC newsletter

December 2007

www.lungcancercoalition.com



Professor John Field

The risk model was developed based on a study involving 1736 lung cancer patients and controls, which collated information on a vast array of personal characteristics including smoking histories, occupational histories and other environmental, socio-economic, lifestyle and personal history data.

The study showed that a non-smoker who has other aggravating lifestyle factors can have the same risk of developing lung cancer in a five-year-period as a smoker. Unlike previous risk models, which concentrate on age and smoking, the new LLP risk model therefore relates also to non-smokers.

John Field, Professor of Cancer Studies at the University of Liverpool and Director of the Roy Castle Lung Cancer Research Programme, said: "The LLP Risk Model provides us with a more sophisticated way of identifying individuals within a five-year time frame. Current methods are limited to a patient's smoking history.

"The model can distinguish between high-

NEW LUNG CANCER RISK MODEL MAY IMPROVE EARLY DIAGNOSIS

Two-thirds of lung cancer cases could be detected by screening only 30% of the population, thanks to a sophisticated risk model developed by scientists at the Liverpool Lung Project – the largest lung cancer programme in Europe. The model, which calculates the risk of an individual contracting lung cancer in a five-year period, will make it easier to identify individuals who may benefit from screening.

and low-risk individuals regardless of age and smoking history, assessing those most likely to benefit from a future lung cancer screening programme," he added.

The research programme, based at Liverpool University, was launched in 2004 with a grant of 3 million euros from the European Union. The Roy Castle International Centre for Lung Research and the University of Liverpool co-ordinates the research undertaken by teams of scientists from 12 European centres.

One aim has been to develop a combined molecular and genetic epidemiological model of lung cancer risk, incorporating traditional risk factors such as smoking and occupational factors with molecular and genetic markers, taking into account causal interdependencies and multiple sources of variation.

This particular study was funded by The Roy Castle Lung Cancer Foundation and carried out in collaboration with Cancer Research UK and the Wolfson Institute of Preventive Medicine

Given the high-cost of any population-

based screening programme, the new risk assessment model could offer a welcome tool for narrowing down those who would benefit most from screening.

While the link between early detection and mortality in lung cancer remains unclear, catching more lung cancers at an early stage is likely to be reflected in fewer deaths.

● Liverpool is due to host the first International Lung Cancer conference from 9-12 July 2008, on the theme "Translating basic science into clinical practice". The conference aims to build on past accomplishments and develop future strategies for lung cancer diagnostics and therapeutics.

Further details on www.ilcd2008.com

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THE SURVIVOR WHO JUST KEEPS ON RUNNING

Being diagnosed with lung cancer can be a rude shock. But, weeks later, after half your lung has been cut out in a highly aggressive operation, to be told that you are cured is even more breathtaking. Peter Czanyo got up and just started running. He never stopped.

Everything happened so fast. In April 2003 I was told that I had a lung cancer in its initial phase (T1 M0 N0), and it was a question of months. I was put under immediate observation and tested over and over again. Finally on April 16, half of my left lung was taken out.

The doctors were really surprised. The cancer had not affected the tissues, not even the ganglions, and so they decided not to carry out chemotherapy. "You are cured", they said. Nevertheless they advised me to keep away from stress, slow down and adopt a healthy lifestyle. They highlighted the many risks involved, but it was not so simple. It's true that these things change our lives – like many people who suddenly have to confront something momentous, I felt that I was born again. Humans are inspired by issues that affect them and relate them to death, rather than by merely being under a blue sky.

After having stayed three difficult days in UTI my lungs started to expand. Twenty days later I began to walk and tried to hobble for a few meters. These were cold days, but I felt the need to walk, breathe and get better. I remember my emotions and my tears as I ran without stopping in front of the Presidential Residence. That day I promised that by the end of 2003 I would run a marathon of 6 km.

And this is how it happened. In December 2003, eight months after being operated on, I ran 6 km in 42 minutes. And I kept at it. My next challenge was to travel to Mendoza – an Argentine province in the Andes. There I stood in front of the Aconcagua, the highest mountain of the continent, and pledged that I would continue training until I could climb it. A dream, a delirium or an excuse had began. But I needed an illusion which kept me far from the cancer and close to myself. That's the point.

I kept on running. My doctors were surprised by the speed of my recovery. Of course, my lungs are not in top shape, as I had smoked for more than 20 years, but I managed to

establish a routine involving running 7 km, two or three days a week, and, when I get home, I climb 17 flights of stairs in 2 minutes and 40 seconds. And everyday I do a little bit more.

The Aconcagua is not a dream. It is a part of my therapy, and, even if this is an illusion or a fantasy, I needed to keep it going. I read about its 6962 meters, and dreamt about reaching the top and saying that the Aconcagua is already mine. I just have to go and do it.



Social services helped me. I was given a backpack, thermal clothes and they even paid for my many trips to Mendoza, including the hiring of a guide. In November 2004, I climbed the Comision peak (2100m) and in December 2004 the Lomas Blancas (3850m). In March 2005 I took part in a tough expedition which lasted 7 days – I walked 140 km under extreme temperatures reaching minus 20 degrees, snow storms and impossible routes, until I reached Plaza Argentina (4203m). On two occasions I reached a height of 5000 metres.

I needed to continue and I did continue. I kept on training and running.

I ran several 10 km marathons, and on September 10th 2006 I ran the Buenos Aires Half Marathon – 21 incredible kilometers in a little more than two hours.

With the help of Roche Laboratories, I helped launch the Foundation for Lung Cancer Patients in Argentina on May 11th 2007 and I became its first President. The challenges are huge and there is so much to organise – patients, the medical attention, the psychological support, the defense of their duties, the drugs, the treatments, the prevention, the truth, the support, the website. ... Today we have just started with a few people, but no matter how long we'll have to go, there is always a first step.

I realised that if we succeed it's because our dreams are bigger than all that causes us fear, then that fear will disappear and opportunities will grow. This is the way we should face cancer – dream, grow and address who we are and what we feel, being courageous in our search, strong against adversity, happy in good fortune and get closer to our interior wisdom.

I don't want to forget my first dream of climbing the Aconcagua, and I must continue and wish to demonstrate that it is possible, that life is the most important thing and that living is the aim.



Dr Gianfranco Buccheri (left) and Gianluca Gavatora (right) from ALCASE greet the legendary Kurt Diemberger (centre)

ALCASE GOES ON CLIMBING

Mountain climbing and book publishing continue to form the backbone of ALCASE Italy's work on lung cancer awareness and prevention.

Global alpinist Kurt Diemberger has become the latest actor in ALCASE's love story with the mountain. The Austrian climber is now a living legend, having climbed the highest peak – Everest K2 – and explored some of the most hostile landscapes on the planet, including the Amazon and Greenland.

His travels and exploits are told in his autobiography *Steps into the Unknown* – a perfect title for the mission of ALCASE, where information, awareness and solidarity are the equivalent of rope, ice axes and crampons.

2007 also saw ALCASE enrich its library with some outstanding writing. An anthology of testimonies from people healed of lung cancer, *Vincere il Big Killer (Beating the Big Killer)*, brings together 17 stories of courage and hope. Edited by Gianluca Gavatora, with comments by Gianfranco Buccheri and drawings by Monica Ferrigno, the book blends the three tracks of the mission of ALCASE: advocacy, support and education.

On the side of prevention, two other projects have progressed into little books: *Aria Pulita (Clean Air)*, for elementary schools, deals with the campaign against smoking and includes the best drawings of the children participating.

NON E' MAI TROPPO TARDI.....per fermare il Big Killer (It's not too late to... stop the Big Killer) is a guide for the prevention of lung cancer – a mix of fascinating accounts of the fight against cigarette smoking and basic information on the anatomy and physiology of the lungs and symptoms of cancer, written by Gianfranco Buccheri and Gianluca Gavatora with graphic design by Simona Buccheri.

- *Vincere il Big Killer* (101 pages), available at www.grauseditore.it/ordini.asp.
- *Aria Pulita* (29 pages) and *Non e' Mai Troppo Tardi* (56 pages) can be purchased at www.lulu.com.
- *Passi verso l'ignoto* is published by Editrice Corbaccio.

To mark Lung Cancer Awareness Month at the end of November, the Associação Brasileira do Câncer embarked on an ambitious set of events in six important Brazilian cities. During the whole day, people were invited to talk to oncologists who stood in open spaces and parks, giving out information leaflets. Each event closed with the planting of a tree to symbolise life and the importance of getting in touch with nature.

Earlier, on November 7th, the Tobacco Control Alliance – a network of Brazilian health organisations, including ABC – delivered letters to the Republic's President, Health Minister and Parliament. The letter proposed an amendment to the law related to tobacco-free areas, arguing for adequate legislation to protect citizens from harmful substances of tobacco smoke inside public establishments.

A special edition of ABCâncer Magazine: Advocacy was launched to raise awareness about the importance of understanding the concept of advocacy and modern methods for early detection of lung cancer.

STÖDET CELEBRATES PROLIFIC YEAR

Efforts to get the Swedish cancer society Cancerfonden focused on lung cancer bore fruit when 25 doctors and researchers came together to discuss what can be done. As a result, two young researchers will be funded to study in the U.S.A. for three years. Up till now, only a fraction (0.02%) of the society's huge budget of US\$ 50 million has been devoted to lung cancer research.

Lung cancer day was celebrated with style at one of Stockholm's best restaurants, Berns, attracting over 400 cancer professionals. They came to enjoy themselves but also to listen for a whole afternoon to the elite of Swedish doctors, with lung cancer survivors giving short accounts.

The event was broadcast by Swedish national STV2, moderated by TV celebrity, Ulf Elfving. The major crowd puller on the day was Jörn Donner, producer of the movie *Fanny and Alexander*. A prolific book writer, Jörn has had surgery for lung cancer and is known to be a heavy smoker on TV.

Plans are underway for a TV event to raise money for lung cancer. Singer Pernilla Wahlgren will be the star of the gala.

The year's work will be crowned by the announcement of the winner of a \$7000 prize for the most outstanding work for lung cancer patients. It all goes to show that with small resources, plenty of good will and some luck, lung cancer can be top of the agenda.





Blood test may detect lung cancer early

Researchers at the Duke University Medical Center have developed a blood test that can help detect lung cancer early, without exposing patients to the risks of biopsy and surgery.

They studied four blood proteins, using markers known as CEA, RBP, SCC and AAT, and found that their levels were different in patients with lung cancer as compared to patients of the same age and gender who didn't have cancer, with over 80 percent accuracy, according to lead investigator Dr Edward Patz.

The researchers created a "classification tree" to ascertain a person's likelihood of having lung cancer, based on the levels of each of the four proteins.

Computerised tomography (CT) scans have a very high false-positive rate in identifying lung cancer, which leads to needless invasive and risky procedures.

The researchers will now perform a larger study looking at the use of biomarkers prospectively in patients found to have lung lesions by CT scan. The ultimate goal is to develop a screening system by which patients could have the blood test before imaging, and those found to be in a "high risk bin" would then have a CT scan for further evaluation.

Lung Cancer News 10/12/07

Salad and gardening impact on risk of cancer

The first risk prediction model to examine the effects of diet and physical activity on the possibility of developing lung cancer has been unveiled by researchers at The University of Texas M.D. Anderson Cancer Center.

Data from a case-control lung cancer study involving more than 3800 participants showed that by simply eating four or more servings of green salad a week and working in the garden once or twice a week, smokers and non-smokers alike may be able to substantially reduce the risk of developing lung cancer.

Lead author Michele R. Forman looked at salad consumption and gardening, pairing

lung cancer patients with cancer-free current, former and never smoker counterparts. She found that by including diet and physical activity, the discriminatory power of the model was raised to 64, 67 and 71 percent respectively for never, former and current smokers.

This finding is important, according to the author, because it is applicable to everyone, including the 15 percent of non-smokers who develop lung cancer.

Lung Cancer News 9/12/07

Tobacco deaths to double by 2030

Tobacco-related deaths may double to 10 million a year by 2030 according to Judith Longstaff Mackay, coordinator of the World Lung Foundation global tobacco control programme.

Most fatalities are expected in developing countries whilst cigarette markets are shrinking in advanced economies.

Despite scientific proof of health risks associated with smoking, Mackay said more people were lighting up worldwide, with an estimated 1.64 billion smokers expected by 2030, compared with 1.3 billion today.

According to the 2006 edition of *The Tobacco Atlas*, published by the American Cancer Society, the four countries with the highest number of male smokers – who make up the majority of the world's smokers – are Yemen, Djibouti, Cambodia and China. China and the US are the world's largest cigarette manufacturers.

The report describes China as a "ticking time bomb" with approximately 320 million smokers. It says smoking is responsible for nearly one in five deaths in the United States.

Reuters Health 9/11/07

Retinoic acid therapy inconclusive

New research at The University of Texas M.D. Anderson Cancer Center suggests that treatment with a derivative of vitamin A called retinoic acid may help cut former smokers' risk of lung cancer. It is estimated that nearly half of newly-diagnosed lung cancers occur in former smokers.

The study focused on 225 people who were

once heavy smokers, but who had quit smoking. They received a three-month treatment combining a form of retinoic acid with vitamin E, a different form of retinoic acid given in isolation or a placebo.

Samples of lung tissue taken from all the volunteers before and after treatment were examined, measuring the proliferation of cells by recording levels of a chemical "biomarker" called Ki-67.

Both treatments reduced cell growth in one layer of the lung cells, the parabasal layer but not in the second, the basal layer. More work will be needed before the exact effects of retinoic acid treatment are known, and giving up smoking, according to Cancer Research UK, remains by far the best way to reduce the risk of the disease.

Journal of the National Cancer Institute 7/11/07

Lung cancer genome project discovers new gene

A study of the alterations in the genetic code of lung adenocarcinoma by genome researchers found a host of new genes, including one that controls the growth of cells essential for lung function. It recorded 57 changes frequently associated with the tumours with only about a third of them linked with the 15 genes already known to play a role in lung cancer.

"It is important to find these alterations in the cancer genome because it can tell us about what causes cancer and how to treat it," said Dr Matthew Meyerson of the Broad Institute of the Massachusetts Institute of Technology and Harvard University.

The most common change uncovered is involved in as many as 12 percent of lung cancer tumours. Known as the NKX2-1, the gene controls the activity of alveoli, the tiny air sacs in the lungs. The study suggests this gene can mutate into one that promotes the growth of lung cancer.

The findings are the first phase of the Tumor Sequencing Project, which aims to continue with the cancer genome efforts, including the publication of *The Cancer Genome Atlas*.

Reuters Health 5/11/07

WORLD CONFERENCE REVIEWS PROGRESS

The world's top lung cancer specialists, medical professionals and researchers converged last September on Seoul, Korea for the 12th World Conference – the theme of the conference was Let's Make Lung Cancer History.

Organised by the International Association for the Study of Lung Cancer (IASLC), the conference, which attracted 5000 participants, showcased an outstanding array of new scientific data reviewing prevention and treatment in lung cancer and key clinical trials. Apart from the obvious emphasis on tobacco smoking cessation, there were three important messages delivered at the conference.



Dr Jesme Fox addresses the GLCC symposium at the Seoul world conference

A report on the screening programme with low-dose fine-cut CT scanning provoked a lively discussion. There are now three new trials looking to verify these findings and they must be followed for a minimum of 5 years to show a difference.

The second message was about the increased accuracy in diagnosing and staging of early lung cancer using PET/CT. No one should have a thoracotomy without a preoperative PET/CT which eliminates futile surgeries.

Finally more evidence was presented establishing the role of adjuvant chemotherapy in earlier stages of lung cancer.

Over 200 lung cancer specialists attended to showcase their research, debate abstracts that addressed the latest issues in lung cancer staging, detection, diagnosis and treatment, and participate in the press programme.

● **The GLCC organised its Annual Meeting during the conference, giving their members the chance to network, catch up with old friends and meet new colleagues. It also hosted a symposium at a session entitled "Engaging Patients and the Lung Cancer Community in Improving Patient Outcomes". Maureen Rigney (USA) spoke on the subject of Clinician Communication, followed by Prof. Waun ki Hong (USA) who spoke about clinical trials and patient involvement. Prof. Claudia Henschke (Canada) talked about lung cancer screening and her message to the public, and the last presentation, on clinicians, scientists and lung cancer advocacy, was given by Jesme Fox (UK) and Dr Joan Schiller (USA). Each presentation was followed by a question and answer session. The GLCC information stand attracted many visitors, including a top representative from the Korean Government.**

The GLCC Lung Cancer Awareness Leaflet is now out. Designed to raise awareness about lung cancer it is available in 11 languages: English, Brazilian-Portuguese, Portuguese, Dutch, French, German, Italian, Spanish, Korean, Mandarin and Cantonese.

The leaflet can be downloaded from www.lungcancercoalition.org



Update from the Secretariat



Welcome to our new member from Denmark – the Danish Lung Cancer Association.

Founded in 2005 it has already established itself as an important player in the public debate concerning treatment and care of lung cancer patients and their relatives.

The aims of the Association are to help and assist lung cancer patients and their relatives to live a better life with lung cancer. For this purpose it has set up a "hotline" so that patients and relatives can contact other people who are or have been in the same situation.

The Association arranges meetings and seminars for its members all over Denmark. The topics are new methods in treatment of lung cancer, and other relevant information for lung cancer patients, but most importantly, establishing a network amongst members.

The Association also aims to influence politicians and the health service to focus on the needs of its members, such as adopting new methods of treatment, reducing waiting times for treatment, rehabilitation services, etc.

Every November 17th, the Association arranges a seminar in Copenhagen to mark International Lung Cancer Awareness Day, bringing together representatives from the health services, politicians, patients and relatives, and the media.

For more information please go to the Association's website at www.lungekraeft.dk or www.lunglife.dk

● The GLCC website has now been overhauled. The new site has a more modern look, is easier to navigate and is available in other languages. www.lungcancercoalition.org

Articles, suggestions, or comments for the next issue should be sent to the secretariat.

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AWARD ATTRACTS RECORD ENTRIES

The second Lung Cancer Journalism Award attracted high-quality contributions by health journalists from more than ten countries as far afield as Argentina, Indonesia and China, making awareness of cancer a true global story.

Judges representing cancer professionals, patients and health journalists had to consider over twenty outstanding entries from ten countries – it was not an easy task. As well as measuring creativity, innovation and impact, the panel had to appraise the writing and evaluate the research. On top of this, special criteria were set for each of the three categories.

The Best Consumer Award was won by Nawal Nasr (right). Her hard-hitting, emotional article “One Million Two Hundred New Cases Per Year, and to Blame... the Cigarette,” was published in the Lebanese magazine *Arab Week*. The story used a creative mix of harrowing human stories and case studies, that presented a clear picture of research and treatment options.



The runner up, Elvira Cordelione, wrote an informative and well-researched piece for the Canadian *Toronto Star* “Lung Cancer Poses Deadliest Threat – by Far”.

The Best Medical Award was won by Adi Gazdar, Sophie Sun and Joan Schiller, who wrote for the US *Nature Reviews* an innovative and accurate article, “Lung Cancer in Never Smokers – a Different Disease”, displaying well-argued research.



Michaela Kreuzer from Germany (bottom) was picked as the runner up, for her well-researched and topical piece “Active Smoking, Passive Smoking and Cancer. Current Studies from Germany and their Contribution to the New IARC Monograph” in *The Oncologist*.

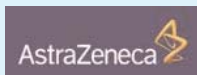


The Best Broadcast Award was won by Malgorzata Kownacka (above), who used her Medical Advice Programme in Polskie Radio to raise awareness of lung cancer by discussing changes in patient prognosis and survival, the risk of passive smoking and the importance of early detection.

The runner up was Emily Easton, from the ITV website in the UK, who produced an emotional and poignant report capturing insights from key opinion leaders, patients and government officials.

An awards ceremony has already taken place in Germany where runner-up Michaela Kreuzer (left) was presented with her cheque and certificate by Dieter Kuerten, the famous footballer. Awards ceremonies are planned in Poland and Lebanon.


The GLCC acknowledges the support of its sustaining partners, AstraZeneca, Roche and Lilly.



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Established in 2001, the GLCC comprises 22 non-government patient organisations in Argentina, Australia, Brazil, Canada, Denmark, France, Germany, Ireland, Italy, Japan, Netherlands, Spain, Sweden, the UK and the US.

 **Fundación Pacientes de Cáncer de Pulmón (Lung Cancer Patient's Foundation):** website in construction

 **Australian Lung Foundation:** www.lungnet.org.au

 **Associação Brasileira do Câncer (Brazilian Cancer Association):** www.abcancer.org.br

 **Canadian Lung Association:** www.lung.ca

Cancer Advocacy Coalition of Canada: www.canceradvocacycoalition.com

Lung Cancer Canada: www.lungcancer canada.ca

 **Patientforeningen lungekræft.dk (Danish Lung Cancer Association):** www.lungekraeft.dk

 **La Ligue Nationale Contre le Cancer (French Cancer League):** www.ligue-cancer.net

 **Deutsche Krebsgesellschaft E.V. (German Cancer Society):** www.deutsche-krebsgesellschaft.de


 **Irish Cancer Society:** www.irishcancer.ie

 **ALCASE Italia (Alliance for Lung Cancer Advocacy, Support, and Education – Italian Chapter):** www.alcase.it

Tribunale per i Diritti del Malato – Cittadinanzattiva (Tribunal for the Rights of Patients): www.cittadinanzattiva.it

 **West Japan Thoracic Oncology Group (WJTOG):** www.lnet.info


 **Longkanker Informatiecentrum (Lung Cancer Information Centre):** www.longkanker.info

 **La Asociación Española Contra el Cáncer (Spanish Association Against Cancer):** www.todocancer.org

 **Stödet (Sweden Lung Cancer Support):** www.stodet.se

 **British Lung Foundation:** www.lunguk.org

Roy Castle Lung Cancer Foundation: www.roycastle.org

 **Lung Cancer Alliance:** www.lungcanceralliance.org

CANCERcare: www.cancer care.org

Cancer Research and Prevention Foundation: www.preventcancer.org

National Lung Cancer Partnership: www.nationallungcancerpartnership.org