



GLCC newsletter

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www.lungcancercoalition.com

CHINA ROLLS OUT MODEL TOBACCO HAZARDS STUDY

Nearly 10 years ago, China received a wake-up call when the first population study on the health effects of smoking concluded that deaths from tobacco were set to reach 3 million a year by 2050. The study was coordinated by the Chinese Cancer Institute in collaboration with the Oxford-based trials unit where Richard Doll first established the link between lung cancer and smoking. One of its co-authors Professor Zhengming Chen, spoke to GLCC about the original study and about a more sophisticated study that is currently under way.



The original study collected smoking habits data, retrospectively, during the '90s from the families of about one million people who died of various conditions. It found that 15% of tobacco-related deaths were caused by lung cancer, and that lung cancer rates in those aged 35–69 are about three times as high in smokers than in non-smokers.

Professor Zhengming Chen said the report created a major stir. "Once we had local evidence, it produced an almighty impact in China and spurred the government to act."

A second, prospective, study by the same Oxford unit involving a quarter of a million cohort has just reached 15 years of follow-up. "This one is very complete" he said, "We not only looked at various receptors with relation to smoking but also at alcohol, blood pressure, and BMI." The results are yet to be analysed but some of the findings are yielding similar statistics to the old study, such as low tobacco consumption among women.

He cautions, however, "It is not an ideal population to assess what's going to come

in the future because the smoking habits nowadays are quite different from the old generation." One positive finding is that smoking cessation has increased by 10%.

A third study is now being rolled out which is almost revolutionary in scope and methodology, involving half a million people in 10 regions in China and including a variety of blood-based measurements. "Tobacco is one piece of the jigsaw – perhaps the most important – but also important are alcohol, diet, blood pressure, obesity and psychological factors, physical activities and most crucially biochemistry.

"Hundreds of things you can measure in your blood, your lipid levels, your proteins, your vitamins, your micronutrients, your genetics – this is an evolving area."

One hundred and fifty trained people will travel to local communities to set up clinics where they will invite and enroll local people. They will do interviews and obtain measurements, which they instantly load on their laptops, and finally take a blood

sample. The blood is taken to Beijing for long-term storage. Study progress is monitored in detail on a daily basis in both Beijing and Oxford. The same measurements will be repeated every five years.

This study is breaking new ground and is becoming the gold standard for measuring tobacco's impact in the developing world.

While in the past it was rare to find research studies outside the Western world, many collaborative projects – to assess the relevance of tobacco in local population as well as other risk factors – have now been set up by the Oxford unit, including studies in Cuba, India, South Africa, Mexico and Egypt.

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CONFESSIONS OF A SURVIVOR

At the last gathering of ECCO – Europe’s largest cancer conference – Anders Jonasson, survivor and founder member of the Swedish lung cancer group Stödet, spoke to the media at the ECCO Patients Forum press conference. He highlighted unacceptable differences in the quality of care and called for easy access to a second opinion and for adequate funding for cancer care.

In 1999, I was operated for lung cancer. At check-up I asked the doctor what he was looking at. He said he was looking at the lungs and liver, but he wouldn't look behind the breast bone, because even if he found something, there would be nothing he could do.

In spring 2002, I found I had a metastasis behind the breast bone, and it was as big as an orange.

I got the message about this inoperable, incurable metastasis one week before my daughter was born. When we came to the hospital for her birth, I was so confused I didn't know whether I should be happy or sad, so I asked the nurse to give me something to calm me down. She looked at me and said "Well we don't usually give that to the fathers." But I explained my situation and got what I asked for.

The situation for lung cancer patients in Sweden in 2003 was not good. There was no organisation, no one to turn to and no one to speak with. There were, however, some patients who wanted to start an organisation, and there were also some doctors who helped us get it off the ground.

It has now started and is called Stödet – that is Swedish for support. The reasons we started it are obvious. We wanted to help people with lung cancer, and we needed to have an effect on the politics regarding cancer.

We organise meetings in different parts of the country. Usually a lung cancer meeting is similar to this conference, but not as big. We also have a website where we put up news, and we have a freephone which patients can call.

It is very interesting when someone calls after receiving the same diagnosis as I had three and a half years ago. When I tell them I had that diagnosis, I can feel them tensing up, and they quickly ask, "How are you feeling?" I reply "Very good, but I have a little too much work to do." This is not what they expect to hear, in particular after three and a half years. I just had a CT about two weeks ago, and there is no cancer in my lung.

Hospitals in Sweden are generally very good, but there are big regional differences. In one hospital you have one treatment, and in another you have something different. This is not good. We need a national plan or, perhaps, we need a plan at European level, but that is not for me to say. It has to be equal rights for all people.

For example, a woman called two and a half years ago. She was just a little over 50 years of age. She had an adenocarcinoma which had spread. She had been through chemotherapy, but it did not stop the tumour. So they told her "There is nothing more we can do for you. You must go home and prepare for the worst." She called us, and we told her about some new medicines.

In our association, we don't know what treatment to give, but we do know there are new medicines. We also told her

that she has the right to a second opinion. She didn't understand this, but after she took a second opinion, she managed to get the new medicine.

We understand that she is very well today and is working after two and a half years. She is right now on holiday in the Canary Islands and is feeling fine.

Another example was a man, calling from the same area, from the same hospital, and even using the same doctor. He had the same diagnosis, and from what I understood, about the same spread in the lungs. So I asked him whether they had talked about these new medicines. He promised to find out and he called again after one week saying "Yes, the doctor is considering giving me this medication in the autumn." This was in March.

Unfortunately he died two months later. So here we had the same hospital and even the same doctor, who first does not give the drug, then considers giving the drug, but the patient didn't have time for this consideration.

It is very important to trust your doctor, and the Swedish doctors are very good. But patients also have to know that they have a right to a second opinion.

There is something starting in November called *2ndView* involving 25 experts, oncologists, urologists, etc. To me this is a very good idea, and it shows that we need a national cancer plan, at least in Sweden. The founding members are very big names in Swedish oncology.

I want to say one more thing. I get angry when I hear that people with cancer talk about money and cuts. What is more expensive than life? Nothing.



NO ONE DESERVES LUNG CANCER

Lung cancer patients, the disease and its treatment, received a rare and welcome flurry of publicity in the Swedish media after the Swedish Cancer Society highlighted the problem, for the first time ever, in their annual report. For the lung cancer organisation Stödet, this was a breakthrough they'd long been working for.

After years of hard slog, activists from the Swedish patients organisation, Stödet, trying to raise the profile of lung cancer, have something to smile about. The key message that "no one deserves lung cancer" has finally been taken up by the Swedish Cancer Society, the largest fundraiser for cancer research in Sweden in their annual report. And the message was picked up and spread all over the media.

"Believe it or not, headline news of the major public television channel TV2 was that lung cancer can be cured!" enthused Anders Jonasson, a cancer survivor and one of the most active members of Stödet.

Lung cancer was the topic of the day on many television channels and in several newspapers that week. And there are high hopes of more to come.

"Since all this action occurred, I believe it will be a lot easier for us to keep up the good work in Sweden, and hopefully internationally as well. The media is finally listening to us. Policy and decision makers are listening to the media," said Jonasson.

But it is not only journalists who have for many years failed to grasp the issues involved. A prominent oncologist admitted that several of his colleagues still do not understand that there has been a massive improvement in the treatment of lung cancer patients during the last few years. Due to this ignorance, lung cancer is being treated differently in different hospitals across Sweden. This is seen as a real problem in a country where healthcare

is supposed to be free and of equal standard for all citizens.



Välkommen till STÖDET

Journalists also set out to challenge the misplaced attitudes of blame and shame that has so long been attached to lung cancer. "The issue of shame should really be a non-issue," said Jonasson, "and the key message that 'no one deserves lung cancer' has started slowly getting through."

"Remember that all sorts of cancer were seen as shameful in the fifties and sixties. Remember how HIV and Aids were perceived in the beginning. It is very important that we, advocates for lung cancer, keep up our work."

For the first time a debate has opened up over what level of resources are needed. A 20 or 30 percent increase will not do, according to Stödet. They have been calling for a total review and fundamental change. They argue that in Sweden eight people a day die from lung cancer and at least one or



two could be cured with better medical care.

About nine years ago, care organisations sat down together with leading lung cancer specialists and calculated how long it should take between the different stages in the investigation of a suspected lung cancer in a patient. They decided that 21 days was a reasonable timespan between the day of notification to a specialist and the day a treatment plan should be ready, and agreed that this time-span should be achievable for at least 80 percent of the patients. At the same time the same doctors also initiated a national quality register of all lung cancer patients in Sweden.

Thanks to that register, official figures are now becoming available on the time lag from diagnosis to treatment plan. "The picture they show is devastating," says Jonasson. It takes 60 days until 80 percent of patients get a correct diagnosis and a treatment plan. With such a severe disease as lung cancer, where the stages between one and four is life decisive, that is definitely not OK. Not by a long way!"

The register has been a great help for Stödet because it provides figures that are clear and easy to understand. The survival rate for lung cancer in Sweden is probably no worse than rates in other countries, and it is therefore likely that the issues highlighted by the register are problems in other countries as well. "Perhaps the key is to make everybody in the world really understand that 'no one deserves lung cancer,'" concluded Jonasson.

● Anders Jonasson can be e-mailed at anders.jonasson@stodet.se and is keen to exchange views and information.

Vincere il Cancro del polmone: An anthology of winning stories, told by lung cancer survivors

A new book "*Vincere il cancro del polmone*", a collection of testimonies of lung cancer survivors, is the latest ambitious editorial effort by ALCASE Italia. Compiled by Gianluca Gavatorta, the seventeen true stories sketch a touching picture of trust in doctors and support from friends and loved ones. "The aim is to heal the spirit of newly diagnosed patients... to show them that, "If birds fly, it must be possible to fly!"

Published by Graus Editore, with a preface by Professor Giorgio Scagliotti of Turin University, the book is available from major book shops in Italy. Price euros10.

● CancerCare in the US has started reorganising its website to make it easier for patients and family members to access its services. The new version of its dedicated lung cancer site, www.lungcancer.org is scheduled to launch in November 2007 during Lung Cancer Awareness Month.



Risk prediction model soon to be accessible

A prediction tool which identifies smokers at higher risk for developing lung cancer is being constructed and validated by researchers at The University of Texas M. D. Anderson Cancer Center.

The risk assessment tool was developed and tested by comparing the medical history of 1,851 lung cancer patients treated at M. D. Anderson with the same data from 2,001 matched healthy individuals. Former and never smokers were all included for the first time in the development of a risk assessment model.

Based on the model, clinicians can compute a patient's ordinal risk score and absolute chance a patient has of developing lung cancer within a year. The patient then can be classified into high-, moderate-, or low-risk groups.

Currently, the researchers are developing a Web-based version of this lung cancer assessment model, and hope to make the tool accessible soon to clinicians.

From the Journal of the National Cancer Institute 2/5/07

Statin drugs linked to lower cancer risk

New research shows that cholesterol-lowering drugs called statins may slash a person's chance of developing lung tumors in half. The findings, first reported in 2005, come from an analysis of nearly half a million patient records collected from 1998 to 2004 in eight southern states. An updated report was filed recently by the research team led by Dr Vikas Khurana of the Overton Brooks VA Medical Center in Shreveport, LA and colleagues.

They reported that people who take cholesterol-lowering statin drugs for more than six months cut their lung cancer risk by 55 percent. Taking the drugs for four or more years cut lung cancer risk by 77 percent. Statins, one of the most highly-prescribed drugs to treat high cholesterol, include Zocor, Lipitor, Pravachol, Crestor, Lescol, and Mevacor. Previous studies have suggested that statins may cut a person's risk of many other cancers, including breast cancer, colon cancer,

prostate cancer, brain cancer, kidney cancer, and leukemia.

Though the lung cancer data are compelling, the researchers estimate that it's still too soon to recommend that people at high risk of cancer start taking statins for their anti-tumour properties.

"Right now, if you need to be prescribed a drug for cholesterol lowering, many studies suggest you would be better off choosing a statin for its cancer-preventive effect," Khurana says. "But we're not yet ready to prescribe them to [people without high cholesterol]."

From Chest 1/5/07

Relative of patients with early onset lung cancer at risk

People with close relatives with early-onset lung cancer are more likely to develop other types of cancer revealed a study by Dr Michele L. Coté and colleagues from Wayne State University in Detroit, USA.

The study involved 673 subjects with lung cancer diagnosed before age 50, as well as 3,556 parents and siblings. A control group included randomly selected 773 subjects, with information for 3,943 first-degree relatives.

Relatives of the lung cancer case were found to be at almost double the risk for lung cancer compared with "control" relatives.

The types of cancers involved differ between sexes and races. Female relatives had twice the risk for endometrial cancer while African-American relatives were at significantly higher risk for head and neck cancers, lung cancer, and tobacco-related cancer.

The researchers concluded that the familial clustering may reflect inherited susceptibility.

From Chest 1/5/07

Cannabis ingredient shown to inhibit growth and metastasis of lung cancer

Cannabis may be bad for the lung but the active ingredient in marijuana may help combat lung cancer. Researchers at Harvard University presented to the annual conference of the American Association for Cancer Research results of their tests which showed that delta-tetrahydrocannabinol (THC) cuts tumor growth in common lung cancer in half and significantly reduces the ability of the cancer to spread.

According to Dr Anju Preet and colleagues tests on mice that have been implanted with human lung cancer found that tumours were reduced in size and weight by about 50% in treated animals compared to a control group. The researchers suggested that THC

inhibited EGF-induced growth and migration in epidermal growth factor receptor (EGFR) expressing non-small cell lung cancer cell lines, although they do not know why. More is needed to clarify the pathway by which THC functions.

From Medical News Today 23/4/07

Diabetes drugs may lower risk of lung cancer

The use of diabetes drugs called thiazolidinediones, such as rosiglitazone (Avandia) and pioglitazone (Actos), may reduce the risk of lung cancer, according to the preliminary findings by Dr Rangaswamy Govindarajan from the University of Arkansas for Medical Sciences, Little Rock, USA.

The study investigated the effect of thiazolidinediones on the risk of lung, prostate, and colon cancer in men aged 40 years and older with diabetes, using a database covering 87,678 individuals. They found 1,137 cases of colon cancer, 3,246 cases of prostate cancer and 1,371 cases of lung cancer. Taking account of other risk factors the research reported that patients who were prescribed thiazolidinediones had a 33 percent lower risk of lung cancer than patients who were not prescribed the drugs. Lung cancer reduction was found to be greater among African Americans.

However Govindarajan urged caution asking physicians not to start using these agents for cancer prevention and calling for further studies.

From the Journal of Clinical Oncology 20/4/07

Depleted uranium weapons linked to lung cancer

Previous research by the US government on the risk of cancer caused by depleted uranium (DU) were debunked by the first study of DU's effects on human lung cells by toxicologist John Wise and colleagues at the University of Southern Maine in Portland, USA.

In this study, cultures of human bronchial fibroblasts were exposed to particles of uranium oxide typically found in DU dust. As a result, chromosomes in the cells mutated and the cells died. Further the genotoxic effects increased with the particle concentration, thus raising a person's risk of lung cancer, concluded the team.

Depleted uranium is a dense, weakly radioactive metal used in armour-piercing shells. Hundreds of tonnes of them were fired by US and UK forces in Iraq in 2003. Despite governmental denials, DU has long been suspected a human carcinogen, affecting the bronchial cells of the lung.

From Chemical Research in Toxicology 14/4/07

Dutch patients tell their LONGstories

During World Lung Cancer Month last November, the Lung Cancer Information Centre (LIC) in the Netherlands launched a new initiative to enhance general awareness and understanding of lung cancer, and at the same time support lung cancer patients.

LONGstories ('long' is Dutch for 'lung') is all about the personal stories of people with lung cancer and of their loved ones. Each of them deals with the disease in a unique way. The project has assembled these personal accounts and commissioned artists to present their interpretation of the stories, translating the feelings expressed into pictures. Thus, story and artwork combine to form a single image, a LONGstory.

'LONGstories' is a unique cooperation between people confronted with lung cancer and prominent visual artists. It is intended to be a long-term project, with new LONGstories being added over the coming years, each contributing to a greater awareness of the serious situation faced by lung cancer patients and the support they need and deserve.

LIC chairperson, lung specialist Ernst Lammers, said, "By bringing these stories and works of art together, a stage is created by patients for patients, on which they are being heard and seen and to which we aim to attract a lot of attention on the Internet and in the media."

LONGstories will soon have its own Internet site, www.longstories.nl, dedicated to showcasing the growing collection and how it has been created. TV and printed press are encouraged to cover this unique collaborative process.

A robust PR campaign is planned to highlight the project, including the publishing of a book, a compact mobile exhibition, and free 'boomerang' cards – eye-catching publicity postcards that are distributed through hotels, restaurants and bars.

Looking ahead, the LIC is set to organise a special event in November, probably an exhibition at TORCH, one of Amsterdam's famous art galleries. Its owner Adriaan van den Have acts as an ambassador for the project, motivating well-known artists who have an empathy with the participating patients and their stories to contribute to the programme.



So far the response has been very positive. The LIC has welcomed the tremendous support and effort of the people sharing their ways of dealing with the disease, of the artists who have already signed up, and of Adriaan van den Have of the Torch gallery.



Eelco Brand is the most recent exhibitor at the Torch gallery in Amsterdam. *Sparbos 2*.

Update from the Secretariat



Welcome to our new member from Ireland, the Irish Cancer Society.

The ICS is the national charity dedicated to eliminating cancer as a major health problem and to improving the lives of those living with cancer.

Most of its work on lung cancer is featured in a 79-page booklet entitled *Understanding Cancer of the Lung*, which can be down-loaded from their website www.irishcancer.org.

In 2004 the ICS was part of a pro-health alliance, which supported a workplace smoking ban. This ban led to a reduction in smoking, despite the government failing to increase the price of cigarettes. In successive budgets the price of cigarettes fell in real terms, resulting in a resurgence in smoking.

Following extensive lobbying from the Irish Cancer Society, the government increased the price of 20 cigarettes by 0.50 euros in the most recent budget.

The ICS also delivers the national smoking quitline in partnership with the Health & Safety Executive. It has taken over 50,000 calls since it was set up in November 2003.

The society operates a freephone National Cancer Helpline offering advice, support and information.

- The next Global Lung Cancer Coalition Annual Meeting will be held in Seoul on September 2nd at the Marriot Hotel, prior to the 12th World Conference on Lung Cancer. GLCC will host a symposium at the conference on September 3rd from 10.15 am to 12.15 pm. Invitation and registration forms have been sent to all members.

- Work has begun on the Lung Cancer Awareness-Raising Toolkit. The first draft was received and circulated to the Executive Committee. Although some re-draft will be required, the final document should be available by early summer.

Articles, suggestions, or comments for the next issue should be sent to the secretariat. Copyright 2007 GLCC

WOMEN UNITE TO DEFEAT LUNG CANCER

The Roy Castle Lung Cancer Foundation launched a major campaign last September to mobilise women behind the cause of defeating lung cancer. Women Against Lung Cancer is fronted by the Oscar-winning actress Dame Judi Dench who lost her husband to lung cancer six years ago.

The campaign's four-point pledge focusses on raising awareness, increasing funding for research, ensuring best treatment and care for lung cancer patients and freeing them from blame and stigma.

Women Against Lung Cancer, includes lung cancer patients and carers, cancer nurses and supporters of The Roy Castle Lung Cancer Foundation.

One of its first big events was a meeting organised in the House of Lords, in March to inform parliamentarians about the progress made since the launch of the campaign six months previously.

The head of Women Against Lung Cancer, Dame Gill Oliver, explained why there is a need for the campaign. "Lung cancer is the number one cancer killer of women – responsible for nearly one in five of all female cancer deaths in 2004 and claims more women's lives than breast cancer in the UK," she said, adding that, "Almost twice as many UK women die from lung cancer when compared to other European countries."

Baroness Jay of Paddington, who was a health minister in 1997, spoke of the great progress that has been in breast cancer over the past 10 years and said lung cancer, which is no less deserving, could learn from these successes.

Dr Marianne Nicholson, a leading oncologist at Aberdeen Royal Infirmary, talked passionately about the need for campaigning in order to

attract resources for lung cancer patients.

Sharron Heginbottom, a lung cancer patient and trustee of The Roy Castle Foundation, gave a personal account of her fight against the disease, which clearly connected with other patients in the room.

The guests welcomed a surprise announcement that international golfer



Dame Gill Oliver leads the campaign.


Colin Montgomerie has agreed to join forces with the Foundation to establish a UK Centre of Excellence for Lung Cancer Patients, based in Glasgow and named "The Elizabeth Montgomerie Centre" after Colin's mother, who died of lung cancer in 1991.

A website has been set up by the Foundation which allows women to sign up as members. Membership is free but donations are encouraged. The website urges members to campaign by sending an email to their member of parliament and/or European parliament, and signing an online petition.

For more information see www.walcuk.org.uk.



Established in 2001, the GLCC comprises 21 non-government patient organisations in Argentina, Australia, Brazil, Canada, 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.ca

 **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.cancercares.org

Cancer Research and Prevention Foundation: www.preventcancer.org

National Lung Cancer Partnership: www.nationallungcancerpartnership.org

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