



GLCC

newsletter

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www.lungcancercoalition.org

GENOME STUDY GIVES GLIMPSE OF THE FUTURE FOR LUNG CANCER MEDICINE

In a breakthrough study by researchers led by a team from the Wellcome Trust Sanger Institute, a comprehensive analysis of a lung cancer genome and a malignant melanoma revealed for the first time all the mutations in the genomes of the two cancers.

Published online in the scientific journal *Nature*, the research was hailed as a breakthrough that will eventually lead to tailored treatments based on the mutations identified in their cancer.

Using powerful new DNA sequencing technologies to unlock completely the genetic codes of both tumour tissue and normal tissue from a lung cancer patient, and by comparing their genome sequences, the study uncovered all the mutations, producing a rich description of the genetic changes in the development of the cancer.

The scientists found the DNA code for lung cancer had more than 23,000 errors largely triggered by cigarette smoke exposure. From this, the experts estimate a typical smoker acquires one new mutation for every 15 cigarettes they smoke. Although many of these mutations will be harmless, some will trigger cancer.

Speaking to the BBC, Sir Mark Walport, Director of the Wellcome Trust, emphasised the excitement and hope for the future generated by

this breakthrough." This is the first glimpse of the future of cancer medicine, not only in the laboratory, but eventually in the clinic. The findings from today will feed into knowledge, methods and practice in patient care," he said.

Scientists around the globe are now working to catalogue all the genes that go wrong in many types of human cancer. Britain's scientists will be looking at breast cancer, Japan's at liver and India's at mouth, while Chinese scientists will study stomach cancer and the US the brain, ovary and pancreas.

The ultimate aim will be for these catalogues of mutations to provide insights into the biology of cancer and become the foundation for understanding cancer causation and improving prevention, detection and treatment.

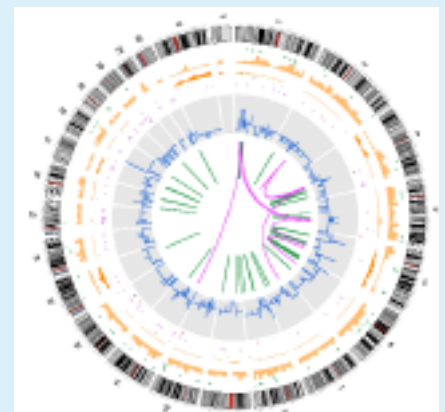
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The catalogue of somatic mutations in a small-cell lung cancer genome

Dr Jesme Fox, Medical Director at The Roy Castle Lung Cancer Foundation, said "Unlocking the DNA code for lung cancer has caused considerable excitement in the scientific community. All of us who work in the lung cancer field are well aware of the devastating impact this disease can have on patients and their families. We are hopeful, that this scientific breakthrough will be the starting point for new developments, which will dramatically improve future outcome for the disease."

The *Nature* article is available at www.nature.com doi:10.1038/news.2009.1143

Courtesy of the Wellcome Trust Sanger Institute

Anders Jonasson

In memoriam

29. 01. 1955 – 09. 08. 2009

A strong voice in the fight against lung cancer has become silent; our friend Anders died on August 9th at home, from internal bleeding.

Anders was one of the founders of the Swedish Lung Cancer Advocacy, Stödet, and its chairman until his untimely death. In him, patients and their relatives found not only a person with great knowledge about lung cancer and the labyrinths of the Swedish health system but a warm-hearted and generous personality.

His daring soul never hesitated to challenge doctors, clerks and politicians and his straight talking won him a lot of respect among nurses and doc-



tors, and helped get the medical community to focus on our disease.

He once remarked that he was "Almost grateful for the cancer". It made him realise parts of life that we normally don't consider until we, or our relatives, are stricken with illness; so Anders realised that he had a mission and we, who were lucky to have worked with him, are so grateful for that ! His energy, spirit and devotion are inspiring examples to us all – his friends and colleagues in Stödet.

Tommy Björk

WHAT THEY SAID

Jesme Fox, *The Roy Castle Foundation/GLCC Secretary*:

"Over the years, Anders and I met on many occasions at lung cancer and cancer advocacy meetings, across Europe and beyond. He was a tremendous inspiration to me and always fun to spend time with.

He used his own experience and passion to improve services and outcomes for many others. Whatever the occasion or topic, he always had something significant to contribute. GLCC has benefited much from his wisdom. His sudden death is a great loss."

Maureen Rigney, *Lung Cancer Alliance*:

"Anders' dedication and enthusiasm were an inspiration to us all; he was a special man who was serious about his work, but it was hard not

to have fun when he was around. He will be dearly missed but the good work of Lungcancerföreningen Stödet will go on in his honour and memory."

Win Boerckel, *CancerCare*:

"Anders was a wonderful, engaging and 'larger than life' personality with the merry twinkle in his eyes and his interest in all that went on about him. We have lost a valued delegate and the lung cancer survivors in Sweden an outstanding and faithful advocate."

Regine Deniel Ihlen, *Lungekreftföreningen*:

"He helped us to start our organisation in Norway, it was a privilege to have known him and we are very thankful for all he did for us".

'CANCRO AL POLMONE No grazie'

The Italian anti-cancer group ALCASE made public education and lung cancer prevention the main themes of Lung Cancer Awareness Month 2009.

A one-day public event, repeated every week in a different city, included a showroom with posters and videos highlighting aspects of

the disease and giving basic information on respiratory anatomy and physiology, on pathology and biology, on lung cancer epidemiology, risk factors, clinical presentation and on early diagnosis. Informal slides were presented by a thoracic oncologist followed by a popular question & answer time. More popular still was the screening of *The Insider*, portraying Russell Crowe and Al Pacino and directed by Michael Mann, which makes a powerful exposé of the tobacco industry. For more information please visit www.alcase.it.

National Lung Cancer Partnership Hosts Symposium on Stigma of Lung Cancer

"De-stigmatizing Lung Cancer – Developing a Road Map for the Future: a Think-Tank Presentation" was the title of an interactive forum hosted by the National Lung Cancer Partnership last August at the 13th World Conference on Lung Cancer in San Francisco.

In a roundtable discussion moderated by Mary Ann Childers, speakers and participants addressed head-on the need to unite lung cancer patients regardless of the cause of their illness, to empower them with a voice for advocacy and to combat the perception of lung cancer as a self-inflicted death sentence.

Among the keynote speakers Dr Wayne Steward (University of California) drew parallels between the causes and consequences of HIV/AIDS stigma and lung cancer stigma. He predicted that, once advances in treatment occur, the perception that lung cancer is an untreatable, incurable disease will be countered, thus reducing stigma.

Dr Jamie Ostroff (Memorial Sloan-Kettering Cancer Center) reviewed the growing body of scientific evidence documenting the stigmatisation of lung cancer and the impact it has on patients, as a consequence of effective anti-smoking campaigns. He argued that one way to lessen stigma is to view smoking not as a character flaw, but a biological or genetic predisposition to nicotine dependence.

Both concluded on the importance of developing support programmes that help those affected by lung cancer to manage the self-blame and shame that can accompany the disease.

Slides and podcast of the forum are available at

www.NationalLungCancerPartnership.org

Working Together Learning Together

The US Lung Cancer Alliance and ALCASE Italia joined together for an educational meeting organised by ALCASE Italia, held last October in Fossano in the Cuneo Province of Italy. The meeting, introduced by



Dr Domenico Ferrigno, president of ALCASE, provided a full programme to patients and their families, the wider public and health care professionals. The history, mission, and achievements of the two groups were explained by Dr Gianluca Gavatorta, Head of ALCASE External Communications and Maureen Rigney, LCA Director of Community and Support Services. Dr Gianfranco Buccheri, Director of ALCASE, closed the programme with a review of the history and activities of the Global Lung Cancer Coalition.

LIVING WITH LUNG CANCER

The Danish Patient Organisation for Lung Cancer initiated, last spring, the first ever survey of patients and their relatives to build awareness about lung cancer and improve support.

A total of 600 patients and relatives received a questionnaire, of whom 92 patients and 90 relatives responded.

The survey highlighted how patients and relatives cope in every day life with lung cancer; how they find strength and how they value the help they get from relatives and the professional health care teams.

Results from the survey, presented by Dr Jesper Holst Pedersen at the International Lung Cancer Day in Copenhagen, formed the platform for the awareness campaign 'Living with Lung Cancer'.

The campaign set out to inform decision makers, health care professionals and the public about core issues related to lung cancer and to debunk myths about lung cancer.

The survey provided a good starting point for further improvements in the relations between patients and health care professionals and highlighted the necessity for special support to

families affected by lung cancer. As a follow-up activity a similar survey will be carried out in 2010.

The media outreach of the campaign and the results have already achieved great exposure in both regional and national media. Twenty five articles have been published so far reaching up to 4.7 million readers.

The Danish Lung Cancer Group and the Danish Cancer Nursing Society supported the campaign, and the Danish Cancer Society distributed the results by e-mail to their members.

For further details on the survey, contact the Danish Lung Cancer Association at www.lungekraeft.dk.



EU again rejects Erbitux for lung cancer

German-based pharmaceutical company Merck KGaA announced it will abandon its drug development programme for lung cancer, following another decision by European regulation expert panel, the Committee for Medicinal Products for Human Use (CHMP), to reject its cancer drug Erbitux.

The European Medicines Agency (EMA) first rejected the drug last July expressing concerns that Erbitux provided only a "modest" benefit to lung-cancer patients when added to standard chemotherapy, according to a statement posted on the EMA's website.

Merck hoped to persuade the CHMP, whose evaluation guides EU drug approval, to grant a recommendation for a subgroup of lung-cancer patients. The company initially applied for Erbitux to be used in combination with standard chemotherapy against non-small-cell lung cancer, the most common of lung tumours.

Erbitux, which is already approved for use against cancer of the bowel and of the head and neck, is one of Merck's top products with a market worth more than 1 billion euros (\$1.5 billion) in annual sales, even without lung cancer revenue. Further work is being carried out to extend the use of the drug in bowel cancer and against gastric cancer.

"I am puzzled how you can come to this conclusion for this severe disease with the dossier we provided," said Elmar Schnee, head of Merck's drug unit.

From Forbes 19/11/09

Successful first robotic lung-tumour surgery

Groundbreaking surgery using the DaVinci robotic system was performed for the first time at UT Southwestern Medical Center on a 48-year-old man, the first patient to have robot-assisted lung tumour surgery.

The four-armed robot, controlled by a joystick by Dr J. DiMaio, associate professor of cardiovascular and thoracic surgery, allows more flexibility than standard tools.

Diagnosed with colorectal cancer, Craig Harrison already had his colon and several feet of lower intestine removed. Later his doctors found the cancer had spread to his liver, for which he received radio-frequency ablation followed by radiation and systemic chemotherapy.

Soon afterwards scans revealed new spots on his right lung and Harrison decided against having more radiation and chemotherapy, and opted instead for surgery at UT Southwestern, using the latest technology.

Using the DaVinci system meant that the incisions were small, and surgeons were able to remove the entire mass. "For some patients, robot-assisted surgery is an excellent option," said Dr DiMaio. "The technique combines patient-centered advantages plus good visuals and more flexible access in the field of operation."

From Medicalnewstoday 22/12/09

Micro-RNAs suppress tumours

Using a naturally-occurring tumour suppressor microRNA, researchers at Yale Cancer Center reversed the growth of lung tumours in mice for the first time. MicroRNAs are small bits of genetic material most often associated with transmission of information encoded in DNA.

The study, conducted as part of a collaboration between Yale university and Mirna Therapeutics, was reported in the December issue of *Oncogene*, showing that tiny bits of RNA can have an effect in shrinking lung cancer.

The team, led by Dr Frank Slack, found that tumours in mice with non-small-cell lung cancer shrink after delivery of an intranasal dose containing a type of micro-RNA called let-7. The tumours were not eliminated, but reduced by 66 percent.

Further studies are being carried out to find out whether let-7 therapy in combination with chemotherapy and radiation can induce full remission. Mice without let-7 developed cancer, proof that the microRNA acts as a tumour suppressor.

Funding for the work came from the National Institutes of Health, Connecticut Department of Health, The Hope Funds for Cancer Research and Mirna Therapeutics, Inc.

From ScienceDaily 8/12/09

Childhood exposure to second-hand smoking increases risk of cancer in adulthood

A study, published in the December issue of *Cancer Epidemiology, Biomarkers & Prevention*, a journal of the American Association for Cancer Research, has found association between childhood exposure to second-hand tobacco smoke and increased risk of lung cancer in adulthood, even if they never smoked.

Several studies have already shown that exposure to second-hand smoke in adulthood has detrimental health effects, but there were limited data on the risk of developing lung cancer when exposed as a child. And what makes this study different is that it used two independent cohorts and included a molecular analysis of gene variants of innate immunity – the mannose binding lectin-2 gene, or MBL2 gene.

Based on these results, Dr Curtis Harris, chief of the Laboratory of Human Carcinogenesis at the National Cancer Institute, who conducted the study said, "children should not be exposed to secondhand tobacco smoke due to the long-term health implications they can face in adulthood."

From ScienceDaily 4/12/09

Major step towards controlling tobacco

The American Lung Association has welcomed a decision by the US Federal Government to give the Food and Drug Administration power to regulate tobacco, following the signing of new legislation by President Obama last June. The FDA will now have a say in how companies market, manufacture and sell tobacco products.

The Association also welcomed the hike in federal cigarette tax from 39 cents to \$1.01 per pack introduced by the US congress, although it is still short of the state cigarette tax averaging \$2.68 per pack.

Health experts say that higher cigarette taxes can bring pressure on smokers to quit and discourage teens from starting.

From Reuters Health 1/12/09

WIN TAKES ALL

The US Lung Cancer Alliance (LCA) launched last November a new initiative to recognise dedication to lung cancer survivors, the Lung Cancer Support Group Award.

LCA keeps track of all of lung cancer-specific support groups across the United States, regularly updating their list. Through this yearly update, LCA learns which groups have closed, and the main reason cited, which is often lack of participation.

In attempting to understand the challenges that confront support group facilitators, LCA set out to recognise one group each year during Lung Cancer Awareness Month. This year, it seemed only natural that the inaugural support group award be given to Win Boerckel. Win is LiveStrong National Relations Program Coordinator, Lung Cancer Program Coordinator and Social Service Director on Long Island at CancerCare in New York.

Win's group, which started in July 1997, is the longest continuously running lung cancer support group in the US.



Win Boerckel (centre) was presented his award by Maureen Rigney, Director (left) and Amy Pearson, Associate Director of Community and Support Services at LCA.

Win says the group, which welcomes 11-15 members each week, has evolved from being composed of newly diagnosed and in-treatment participants to one that also includes long-term survivors. Win credits CancerCare's dedication to the group as an important reason for his success. "CancerCare allowed me to keep the group going for months when only three or four members would participate. You can't just open up a group for a few weeks and expect it to be an instant success," he said.

Update from the Secretariat



Welcome to APOZ, a new member from Bulgaria. Registered in 2004, the Association of Patients with Oncological Diseases set out to work on four main areas: supporting patients, their families and friends; providing useful patient information; cooperating with agencies to improve prophylaxis; and striving for better services and quality of life for patients. For more information please visit www.apoz.eu.

Annual Meeting

This year's AGM took place at the 13th World Conference on Lung Cancer in San Francisco in July involving 23 delegates and the sustaining partners coming together to share ideas and plan projects for the forthcoming year.

GLCC Symposium

The symposium "Lung Cancer – Overcoming Barriers and Effecting Change" also took place at the same conference and was attended by physicians, nurses, as well as representatives of charities and the pharma industry. They hailed from many regions but most came from North America and Northern/Southern Europe. Speakers included Dr Thierry le Chevalier (France), Liz Darlison (UK) and Andy Miller (USA). Matthew Peters (Australia) chaired the meeting and Jesme Fox (UK) facilitated the interactive session which proved very popular.

Lung Cancer Journalism Award

This year's Award will have a new format whereby each member organisation, should they wish to participate, can make an award on behalf of their own organisation in conjunction with GLCC.

Website

An update and revision of the website is under way and will be launched in early 2010. For further information on the Global Lung Cancer Coalition please visit www.lungcancercoalition.org or contact glcc@roycastle.org

LUNG CANCER IN THE NEWS

UK media coverage of lung cancer was again the subject of a research study by CARMA International which was initiated and managed by CancerCare on behalf of advocacy groups. This time the study focused on four cancers – lung, breast, prostate and colon/colorectal – during the period August 1st 2007 till July 31st 2008.

A random sample of 300 stories were researched in a select media list including newspapers, newswires, websites, consumer magazines and broadcast transcripts. For a start, it was found that lung cancer generated the second most stories of the four cancers, but it had, after breast cancer, the worst overall favourability rating and the most negative message. Of these, the message that lung cancer patients are smokers (19 articles) appeared most often, followed by the message that more research needs to be conducted on lung cancer (10 articles).

Few opinion leaders commented on lung cancer, in particular health care professionals, though advocacy groups were featured in 12% of stories. In addition, few stories highlighted celebrities, politicians, or other well-known individuals who suffered from, or overcame, the disease.

Some messages were markedly improved. One-third of all lung cancer articles mentioned treatment of the disease, an increase from 15% of stories in the last analysis. Risk factors were discussed in 42% of stories mentioning lung cancer, compared to only 20% for the other three cancers. Smoking was the primary risk factor discussed in lung cancer stories.

On the whole, the fight against cancer was highlighted more poorly in UK media coverage than in the US. Reports described Britain as among the "worst in the developed world in terms of the proportion of cancer patients who are still alive five years after being diagnosed". Coverage on lung cancer treatment, however, carried a sense of optimism as new technologies promise improved therapies for lung cancer patients.

The full report can be accessed at www.cancercare.org/pdf/cc_uk_mediaanalysis.pdf.

PILOT MODEL SET TO IDENTIFY HIGH-RISK PATIENTS

Once again The Roy Castle Lung Cancer Foundation is in the forefront of research being carried out to defeat lung cancer.

The Liverpool Lung Project (LLP) developed the LLP Risk Model, which is currently being piloted in a high-risk General Practice in Northern England to identify those people who have a high risk of developing lung cancer within the next five years.

This has now been taken to the next level, with the addition of a risk factor that looks at genetic as well as biological reasons for the disease.

The original model was based on a questionnaire which considered factors such as family history, previous malignant disease, history of pneumonia, occupational exposure to asbestos, and smoking status.

Liverpool was chosen for the study because its lung cancer incidence rate is amongst the highest in the UK. It was felt a strong model could be developed that could then be applied across the whole of the UK without underestimating the risk.

The extended model, which includes a particular genetic risk factor (SEZ6L), has been shown to provide an even more accurate prediction of risks. This model is particularly useful for correct grouping of individuals



Dr Olaide Raji

who do not immediately fall into the "high risk" or "low risk" group and selection of a 'high risk' group who would traditionally be very difficult to diagnose at an early stage of the disease.

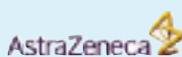
The Foundation works collaboratively with scientists around the world and was therefore delighted when Dr Olaide Raji, from the Roy Castle Lung Cancer Research Programme, was chosen to present the findings in San Francisco in August.

Dr Raji said, "I was privileged to present the work at the International Association for the Study of Lung Cancer World Conference where it was extremely well received, our efforts were commended and deemed to constitute a valuable approach in improving the accuracy of risk prediction models."

What this means for the future is that we should be able to identify high-risk and potentially medium-risk individuals who we need to screen and then monitor for signs of lung cancer.

These are individuals who would otherwise be at risk of not being diagnosed until it was too late.

The GLCC acknowledges the support of its sustaining partners, AstraZeneca, Glaxo-SmithKline, Lilly, Merck Serono and Novartis.



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ABOUT US

Established in 2001, the GLCC comprises 26 non-government patient organisations in Argentina, Australia, Brazil, Bulgaria, Canada, Denmark, Europe, France, Germany, Ireland, Italy, Japan, Netherlands, Norway, Slovenia, Spain, Sweden, the UK and the US.

 **Fundación Pacientes de Cáncer de Pulmón:** www.fundacionpcp.org

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

 **Associação Brasileira do Câncer:** www.abcancer.org.br

 **Bulgarian Anti-Cancer Patient Association (APOZ):** www.apoz.eu

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


Cancer Advocacy Coalition of Canada: www.canceradvocacycoalition.com

Lung Cancer Canada: www.lungcancer canada.ca

 **Patientforeningen lungekraeft.dk:** www.lungekraeft.dk


 **Women Against Lung Cancer in Europe:** www.womenagainstlungcancer.eu

 **La Ligue Nationale Contre le Cancer:** www.ligue-cancer.net

 **Deutsche Krebsgesellschaft E.V.:** www.deutsche-krebsgesellschaft.de

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

 **ALCASE Italia:** www.alcase.it

 **Tribunale per i Diritti del Malato – Cittadinanzattiva:** www.cittadinanzattiva.it

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

 **Longkanker Informatiecentrum:** www.longkanker.info

 **LungeKreft Foreningen:** www.kreftforeningen.no


 **Slovenia-NAVDH (INSPIRE):** www.na-vdih.si

 **La Asociación Española Contra el Cáncer:** www.todocancer.org

 **Stödet:** 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
Prevent Cancer Foundation: www.preventcancer.org

National Lung Cancer Partnership: www.nationallungcancerpartnership.org