ECL ANNUAL CONFERENCE REPORT 2017

IS CANCER IN CONTROL?

ECL Association of European Cancer Leagues

Danish Cancer Society

Copenhagen, Denmark

28 September 2017

CONFERENCE AGENDA

10.00 - 10:25: **WELCOME**

- Dorthe Gylling Crüger, Chairman, Danish Cancer Society
- Sakari Karjalainen, President, Association of European Cancer Leagues
- Christel Schaldemose, MEP (TBC)

10:25 – 12:30: **TRANSFORMATION OF EUROPEAN CODE AGAINST CANCER**

Cancer prevention Europe – a new initiative in Prevention and communication
- Chris P. Wild, Director, International Agency for Research on Cancer (IARC)

From research hypothesis to public health changes the whole grain story
- Anne Tjønneland, Head of Research, MD, PhD, DMSc, Danish Cancer Society

HPV- vaccines – results and challenges
- Mette Lolk Hanak, Head of Prevention, Danish Cancer Society

12:30 – 13:30: Lunch

13.30 – 14.30: **TREATMENT**

Equal access to medicines & ECL Task Force
- Michel Rudolphie, CEO, Dutch Cancer Society

Public Priority of Cancer Medicines in Denmark
- Dorthe Crüger, Chairman of the Danish Cancer Society, CEO Hospital Lillebælt , MD PhD.

14.30 – 14.45: Coffee Break

14.45 – 15.45: **DIVESTING IN TOBACCO INDUSTRY**

What could bring an oncologist to the table in the boardrooms of some of the world's largest and most influential pension funds /finance companies?
- Bronwyn King, Founder and CEO, Tobacco Free Portfolios

15:45 – 16:45: **PATIENT SUPPORT**

Resilience and Cancer
- Head of Cancer Counselling Centre, MS (psych) Peter Genter

Collective Impact - a new approach to solve complex problems
- Ass. Director Elsebeth Kirk Muff, Social Development Centre SUS

16:45 – 17:00: **CLOSING**, Sakari Karjalainen, ECL President

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Welcome and introduction

- Dr Dorthe Crüger – Managing Hospital Director at Hospital Lillebælt, Region Syddanmark, and Chair of the Danish Cancer Society

As the host of this year's annual meetings, Dr Dorthe Crüger formally opened the ECL annual conference and welcomed all participants to the headquarters of the Danish Cancer Society in Copenhagen.

For almost 90 years, the Danish Cancer Society has been the foremost cancer organisation in Denmark, and have engaged heavily in research, treatment, and patient support. Notable successes for the society have been the founding and hosting of, for many years, the national cancer registry, and the extensive advocacy work conducting in the development of the national cancer plan, which was first launched in the year 2000.

But the successes of the Danish Cancer Society have not been earned alone. The society believes strongly in the benefits of collaboration at local, national, and international levels. For this reason, the society is proud and honoured to have been selected as the host organisation of the 2017 ECL annual scientific conference.

- Dr Sakari Karjalainen – Secretary General of the Finnish Cancer Society, and current ECL President

The title and theme of this year's annual scientific conference: "Is Cancer in Control?" In his introductory statement, current ECL President Dr Karjalainen acknowledged that this is a pertinent question to ask when one considers the increasing cancer burden. For example, in 2013 alone, 21.7 million new cases of cancer were diagnosed, and 13 million deaths were attributable to cancer. But what can be done to slow this down?

To address this central question, and examine the steps that needed to be taken to arrest the pace of the cancer burden worldwide, several outstanding speakers were invited to present at the conference, not least **Dr Chris P. Wild** (Director of the International Agency for Research on Cancer - IARC) and **Dr Bronwyn King** (Founder and Chief Executive Officer of the Tobacco Free Futures and radiation oncologist at The Peter MacCallum Cancer Centre and Epworth Healthcare, Victoria, Australia).

These and other distinguished speakers were asked to address several key issues, namely: cancer prevention and health promotion; tobacco control; access to cancer medicines; and support for cancer patients and their families. These issues are central to addressing cancer control and remain the fundamental aspects on which ECL continues to work.

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- **Session 1: Transformation of European Code against Cancer -** session Chair: Dr Hans Storm, Danish Cancer Society
    - **Cancer prevention Europe – a new initiative in Prevention and communication** - Dr Chris P. Wild, Director, International Agency for Research on Cancer (IARC)

Demographic changes and evolving patterns of risk factors will result in major increases in the cancer burden across Europe in the next two decades, while the costs of treatment spiral. This combination is a threat to sustainability of health care systems, indicating **no country can treat its way out of the cancer problem**. The only realistic approach is one that encompasses prevention, early detection and treatment.

Dr Wild highlighted the research of the Globocan initiative, which is a project that aims to provide contemporary estimates of the incidence, mortality, and prevalence from major types of cancer, at national level, for 184 countries. What is often neglected amongst this data is the 5-year prevalence, which indicates that 7 million people in Europe are living with cancer, and that this will very likely rise over the coming years.

Alongside the serious personal cost to cancer patients and their families, there is also a considerable economic cost attached the cancer burden. The productivity loss in 30 European countries in 2008 due to cancer-related mortality was €75 billion, averaging approximately €219,000 per cancer death. Such figures illustrate the growing importance for clinical and public health research to better demonstrate the economic cost of cancer, especially the productivity lost to people being out of the workforce.

Cancer prevention efforts in Europe would be strengthened by bringing together the diverse skills and partners needed under an integrated plan, which avoids duplication and inefficiencies. Prevention works, but takes time and requires a clear vision and committed leadership. In this context, a number of leading cancer research organizations have joined together to create a consortium, Cancer Prevention Europe (CPE) to complement the existing Cancer Core Europe consortium. This twin-track initiative (CPE and CCE) will build on the recognition that cancer biology is providing a “common soil” which can benefit both clinical and population approaches to cancer control.

The objective of CPE is to reduce mortality and morbidity from cancer through primary prevention and earlier diagnosis at pre-malignant stages. This will be accomplished through research into the identification of novel targets for prevention, research into optimising the implementation of known preventive strategies and dissemination of established best practices in prevention.

The CPE partners wish to develop compatible infrastructures; common platforms for conducting prevention and implementation research; high standards of evidence review and dissemination practice.

CPE will focus not just on health outcomes but also on economic issues, demonstrating the cost-effectiveness of interventions, in relation to costs of treatment, care, and productivity. In the first phase of CPE, the partners will publish a position paper (draft being finalised) demonstrating the plan for action for CPE. An advocacy strategy will be defined to identify key stakeholders, prevention sessions at key conferences, etc. In addition, a central website and data information hub, collating information on preventative interventions with proven evidence of benefit, will be developed.

In conclusion, it is important to not lose sight of the fact that, as the European Code against Cancer states, up half of all cancers could be prevented if the knowledge about risk factors were translated

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into practical action. Therefore, part of the goal of CPE will be to encourage researchers to think more about taking the research into the application phase, so that more proven cancer prevention interventions become national programmes.

- **Session 1: Transformation of European Code against Cancer -** session Chair: Dr Hans Storm, Danish Cancer Society
    - **From research hypothesis to public health changes – the whole grain story** - Anne Tjønneland, MD, PhD, Dr.Med.Sci., Head of Research, Danish Cancer Society Research Center

The evolution of the Danish Cancer Society's work to promote greater consumption of whole grain foods offers a best practice example of how innovative research can be taken from the laboratory and brought into public health policy at the national level.

The origins of this story lie in the initial observation on dietary fibre intake and colorectal cancer rates in the late 1960s. Dr Denis Burkitt observed a dramatically higher rates of colorectal cancer in comparison with the country today known as Zimbabwe, in which Dr Burkitt was working at the time. The observation of considerably lower intake of dietary fibre in the UK led to the hypothesis of an association with colorectal cancer.

This observation was later taken up by the research community leading to an eventual Cochrane Collaboration systematic review on dietary fibre for the prevention of recurrent colorectal adenomas and carcinomas. However, the RCTs under review were limited by a high rate of loss to follow up, and the use of adenoma polyps as a surrogate endpoint for colorectal cancer.

Fortunately, several high-quality national and international cohorts were available to provide their rich data source. This included the EPIC study (the European Prospective Investigation into Cancer and Nutrition study, covering 10 countries and 500.000 people); and the Danish Diet, Cancer and Health cohort, which followed 57.000 people. These cohorts offered the important biologic samples, lifestyles and food frequency questionnaire, and physical measurements necessary to develop and refine the hypothesis.

Later meta-analyses, conducted in the early 2010s onwards, demonstrated that the source of dietary fibre was of considerable influence on colorectal cancer risk. In particular, cereal fibres and whole grains were associated with a reduced risk of colorectal cancer. This prompted the World Cancer Research Fund to conclude that there was strong evidence whole grains decrease colorectal cancer risk. Their review of evidence reported a 17% reduction in risk per 90 g/day of whole grain intake for colorectal cancer. In addition, whole grain intake also has a beneficial effect on other non-communicable diseases (including myocardial infarction and type-2 diabetes) and overall mortality.

Taking this knowledge into action, the Danish Cancer Society entered into a unique public-private partnership to support the "The Danish Whole Grain Campaign". This initiative has managed to increase the availability of whole grain products in Denmark, and lifted the whole grain intake in Denmark substantially, from 32g per day to the current level of 63g per day, in just 12 years. The target for the short term is for whole grain intake in Denmark to reach 75g per day

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- **Session 1: Transformation of European Code against Cancer -** session Chair: Dr Hans Storm, Danish Cancer Society
    - **HPV vaccines: results and challenges -** Mette Lolk Hanak, Head of Prevention, Danish Cancer Society

The final presentation of the session focused on the challenges for cancer prevention when a successful programme is disrupted, as was the case with HPV vaccination in Denmark recent years.

Each year in Denmark, 15.000 women are diagnosed with abnormal cervical cells, 375 women are diagnosed with cervical cancer (of whom more than half are aged under 50 years of age), and 100 women die of cervical cancer.

As part of the efforts to address the cervical cancer burden in Denmark, HPV vaccination became part of the Danish Childhood Vaccination programme. In 2009, the vaccination was first offered to girls around the age of 12 years. Young women were also offered free vaccination during a period of two years. The program was an immediate success and within a few years, the HPV vaccination coverage was up to 90 % for girls born 1998-2000.

Unfortunately, the success of the programme was short-lived as by 2013 reports about presumed serious side effects began to show. The reports about girls with unexplained symptoms gained massive attention from the press and on the social media. Significant damage to public trust in the programme was incurred by the television documentary “The Vaccinated Girls”. As a result of the negative publicity about the vaccine, the HPV vaccination coverage dropped dramatically and in 2016 the coverage was only 27% for 2003 birth-year group.

In spite of a renewed, positive safety assessment from the European Medicines Agency and strong recommendation of the HPV vaccination from authorities and doctors, the vaccination coverage is still very low. The challenge is how to communicate more effectively especially to the parents of young girls that HPV vaccination is safe and can save lives.

In response to this, the Danish Cancer Society developed a new approach to communicating the benefits of the vaccine, and addressing the public fears about the perceived harms. This approach was in line with the society’s new communication strategy that attempts to communicate using both logic and emotional appeals. Moreover, the new campaign to improve confidence in the vaccine is targeted esêcially at the parents of the girls within the target age range for vaccination. The ultimate goal is to restore the coverage back to minimum 80%. The initial signs are promising, thanks in large part to the considerable effort of the society’s volunteers, but much work remains to be done.

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- **Session 2: Treatment -** session Chair: Prof. Jacqueline Godet, President, French Cancer League
  - **Equal access to medicines & ECL Task Force -** Michel Rudolphie, CEO, Dutch Cancer Society

One of the core aspects of cancer control is the access to effective medicines to treat and control the disease. In a time where cancer incidence has been rising in Europe, treatment has become crucial in controlling the burden of the disease at a national level. Scientific breakthroughs have occurred in the development of cancer medicines, offering new hope to patients where there may have been none before. However, these innovative medicines have in some cases come with a hefty price tag. Although the increase in innovative and promising treatments should be celebrated, patient access and availability should be central to the system. Some of the main contributing factors to this are inconsistent pricing policies that apply to the pharmaceutical industry, fragmented reimbursement decisions in national health bodies and a lack of transparency in the financial investment in research and development of new medicines.

In April 2016, a coalition of ECL members joined forces on the topic of equal access to innovative cancer medicines. The newly formed ECL Task Force aims to facilitate an international network of ECL members to work together towards equal access to cancer medicines for all cancer patients. This presentation focused on international aspects of access to cancer medicines, as well as the work done by the ECL Task Force.

Michel Rudolphie (MR) wondered if the equal access to medicines is a new reality and how we could justify the high prices of medicines. MR took the example of Car T-cell therapy, a living drug, which is perceived as a great breakthrough and shows amazing results. However, the therapy costs nearly a million USD per patient. Furthermore, a new study showed that the drug R&D cost equals around a quarter of the price quoted by the industry figures. MR further elaborated on the example of the Dutch market, where the total of cost of healthcare accounted for 95 billion EUR (5 billion for drugs, out of which 40% are cancer therapies) and which showed an increase of 3000% in cancer expenses in the past 2 years.

In searching for solutions, MR explained what could be done to reach a sustainable access model. According to MR and as stated in the ECL Access to Medicines Task Force's *Declaration of Intent*, the five necessary components include (i) removing dysfunctionalities creating obstacles in the access system; (ii) consider the pharmaceutical industry as a service provider and revealing the transparent prices of medicines; (iii) combining and accelerating access through legislation and other means; and (iv) improving the information flow for patients and subsequently (v) empowering and involving patients in the decision-making while securing their stronger negotiating position. In his conclusions, MR stressed the ECL Task Force's role as urgent and encouraged the group to make sure there was a dialogue with pharma, the European Fair Pricing Network were developed and the patient was mobilised.

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- **Session 2: Treatment -** session Chair: Prof. Jacqueline Godet, President, French Cancer League

  - **Public Priority of Cancer Medicines in Denmark -** Dr. Dorthe Crüger, Managing Hospital Director at Hospital Lillebælt, Region Syddanmark, and Chair of the Danish Cancer Society

Denmark has a long tradition of making rapid and systematic use of new cancer medicines. The last couple of years, new cancer medicines have been avoided as a standard treatment, as the expected effect was little and the side effects considerable. From 2017, the new cancer medicine will also be assessed with a view to costs – so that expensive medicine with limited effect will not be used as a standard treatment. The Danish Cancer Society works for personalised medicines, so the individual patient receives the right treatment – including being able to reject the treatment based on information regarding expected effects and side effects.

Dr. Dorthe Crüger (DC) presented the Danish model for hospital medicines as an example of personalised medicines use. The model is balancing the access and healthcare costs. DC pointed out that the demand for and the cost of health services increased way more than the funding. The strains on the Danish health economy such as the demographic aging (2% increase in cance incidence every year), the higher expectations and increasingly expensive technology, combined with less than 1% of budget increase in healthcare. DC added and example, that the introduction prices per month of cancer therapy increased from 20.000 DKK in year 2000 to 50.000 DKK in 2014.

The seven principles for public priority on hospital medicines are (i) clinical evidence, (ii) independence, (iii) geographical equality, (iv) transparency, (v) timely access, (vi) value of money and (vii) access for all individual patients. DC saw the Gordian knot is between value of money and access for all individual patients. The Danish medicines council provides assessment and summary of efficacy, safety, side effects and life quality. However, the problem is that value for patients and for clinicians can differ. The patient's voice needs to be more prominent.

- **Session 3: Divesting from Tobacco Industry -** session Chair: Michael Henneberg Pedersen, CFO, Danish Cancer Society

  - **What could bring an oncologist to the table in the boardrooms of some of the world's largest and most influential pension funds/finance companies? -** Dr. Bronwyn King, Founder and CEO, Tobacco Free Portfolios

Dr. Bronwyn King (BK), an Australian oncologist and founder and CEO of Tobacco Free Portfolios told the story of how her earliest years in medicine, treating patients suffering from tobacco related disease, inspired to her to collaborate with and seek partners in the finance sector. This unique approach of combining her medical expertise and everyday life is driving change, with almost $5 billion dollars being redirected from investment in the tobacco industry. The finance sector has never before been an active part of the solution when it comes to addressing the global tobacco epidemic, but a new frontier has arrived with more and more finance

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leaders actively distancing themselves and their companies from the tobacco industry.

In Australia, the average age for starting smoking is 16 years and 2 months old, and it is the oldest in the world. In Australia, 2% of boys between 13 and 15 smoke, whereas these figures compare to 41% in Indonesia. It is estimated that 100,000 children start smoking every day. In the 21st century, it is estimated that 1 billion of people died due to tobacco, compared to 100 million in the 20th century.

The finance sector is tangled up with the tobacco industry through pensions, insurance etc. Investors usually tend to go for the easies investment option. So, why the finance sector should make an exception in tobacco? BK explained her main arguments as follows: 1. tobacco is 0 safety product, 2. there exist an international convention on the product's control public = FCTC, and 3. no engagement takes place. Moreover, the engagement with the tobacco industry is contrary to the UN fundamental rights, as tobacco goes against the UN right to health.

BK stressed that there is a need for more cooperation and conversation between health and finance ministries. The future risks are regulatory (the shares are sensitive to change), related to litigation and supply chain. Furthermore, tobacco has a heavy reliance on child labour.

In conclusion, BK with her colleagues started to give out a 'verified tobacco free logo' which can be adopted by companies free of the tobacco link. BK further stressed the need to exclude tobacco companies from sustainability ratings in charts, because the criteria rule that the companies are competing only within their sector - no tobacco companies should be awarded as 'most sustainable'.

- **Session 4: Patient Support -** session Chair: Dr. Vitor Veloso, President, Portuguese Cancer League
    - **Resilience and Cancer -** Peter Genter, Head of Cancer Counselling Centre

Resilience refers to the processes that either promote well-being among cancer patients or protect them against the overwhelming influence of risk factors. There is an increasing research interest in promoting resilience among cancer patients and Peter Genter (PG) presented the Danish pilot study.

Since the 1990s the topic of resilience increased in the titles of social science journals. According to Moskowitz, in the context of challenging medical diagnosis, the resilience can be defined as the ability to maintain normative levels of psychological well-being, or to return rapidly to pre-diagnosis levels. On the psychology perspective, there is the perspective of vulnerability (mental problems, suffering) or the well-being (protective factors). It is mastering the balance between the everyday life and being a cancer patient.

The resilience qualities include control and influence, cognitive flexibility, meaning and values, positive emotions and thoughts, altruism and social network and persistency. The strategies for resilience do not work on their own but it must be connected to the person's effort. PG noted that positive reflections from patients who have attended the resilience course are needed.

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- **Session 4: Patient Support -** session Chair: Dr. Vitor Veloso, President, Portuguese Cancer League
  - **Collective Impact - a new approach to solve complex problems -** Elsebeth Kirk Muff, Associate Director, Social Development Centre SUS

The collective impact approach is based on a committed effort from different organisations and sectors to solve a specific social problem. The Danish Cancer Society is involved in a collective impact project to improve health among socially disadvantaged young people in a Danish municipality. Elsebeth Kirk Muff (EKM) presented the concept and provided practical examples.

To assure a collective impact, we need to mutually reinforce the collaboration among a group of key actors from different sectors to solve a specific common problem. A structured approach to cross sector work with communities on complex/wicked problems, an approach that supports a problem driven access aside from a project-driven access. Not an evidence -based method, nor a management tool.

The Collective Impact is an approach developed in North America and Canada, and now spread across the world. There are 6 dimensions: (i) a common agenda, (ii) shared measurements, (iii) backbone organization (independent, neutral, facilitating, producing knowledge, communication, advocacy and fundraising), (iv) mutually reinforcing activities, (v) a continuous communication and (vi) a participation and involvement of end users.

The economic investment is not enough, it is complex; no single organization can solve the problem alone, the investment is the collaboration between stakeholders. The collective impact requires an investment in collaboration between stakeholders, funders, organizations and end users. The example of New York Juvenile Justice was taken.

However, EKM pointed out that there usually exists an isolated impact (a competition between grantees). The challenges are diverse: losing the right to define the problem, the contradiction of interest or opinions, issues on how to engage with end users and commit the political system, the risk of focus on measurable activities, the process time and financial support for long term efforts, and the delicate role of the foundations as funders, gatekeepers and partners.

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