2016 World Cancer Congress Master Courses

Master Course N°6: European Scholars Advocacy Course
“Advocacy in Action - Interacting with decision-makers to keep cancer high on the policy agenda”

Organised by:

ECL
Association of European Cancer Leagues

Course description:
Policy action and governmental commitment are key to advancing the fight against cancer. As experts in their field, cancer organisations are in a unique position to advocate towards policy makers to ensure policy supports their needs. It is common that policy is drafted at local, regional, national and supranational level and civil society organisations should be aware of and adapt to this.

This master course will guide you on how to do advocacy at the local, national and EU levels, to raise or maintain cancer as an agenda item for policy makers. Experienced advocates working at cancer leagues nationally and at the EU level will teach participants about what is advocacy and how it works at the national and EU levels. Faculty members will show how policy making works at the EU level; how to affect policymaking at the national level and at the European level by sharing experiences and lessons learned. The focus will be on legislative developments in cancer prevention such as tobacco control and sunbeds, as well as access to early diagnosis, curative treatments and palliative care. We will also share our experiences in promoting cancer prevention at the EU and national level using messages in the European Code Against Cancer.

National cancer leagues have a crucial role in society. Although national realities vary from country to country, cancer leagues across Europe are united in their cause to fight cancer and support and empower patients. Sharing experience in advocacy can empower cancer leagues across Europe when engaging with decision makers.

Advocacy areas:
Faculty members will be available to provide training in the following advocacy areas: (This list is not exhaustive; participants can request guidance for other areas if within expertise of a faculty member)
1. Tobacco Control
2. Primary Prevention
3. Screening and Early Diagnosis
4. National Cancer Control Planning (especially addressing access to early diagnosis curative treatments and palliative care)
5. Patient Support and empowerment
**Course objectives:**

At the end of this course, participants
- would have gained new skills to influence decision makers
- would be able to develop strategic alliances and develop advocacy programmes.
- would be ready to share experiences at a full-day in-person workshop at the 2016 World Cancer Congress on how they have learned how to advocate at the local, national and/or European level.

Through a combination of online courses and a full-day in-person workshop at the 2016 World Cancer Congress, you will learn how to advocate at the local, national and European level. Participants will be able to draft an implementation plan on how they would ensure that cancer remains high on the political agenda in their countries.

**Target audience:**
Cancer league leaders, managers, policy and communication officers, health care professionals and other engaged and motivated civil society organisations or individuals wishing to influence policies.

**Teaching methods:**
We envisage that there would be two types of participants:
- Group 1: those requesting more guidance, and
- Group 2: those choosing to complete the course more independently

Those who wish more guidance will be provided with regular feedback. Those who prefer to be more independent will get feedback only when requested. All course participants are expected to complete assignments allocated to them according to their individual profile by faculty members, which will vary and depend upon needs and resources of the participants.

**Assignments:**
The course will consist of self-paced assignments which include
- Reading materials are provided for specific areas. Participants will be allowed to choose the materials most relevant for their work, and associated homework assignments will be assigned for their chosen reading materials.
- Research assignments, e.g., on opportunities and challenges in the participants’ countries
- Videotaped 20-minute lectures (with and/or without slides) by selected faculty members. These will be accompanied by related assignments.
- One livestreamed roundtable at the European Parliament
- One webinar

Course assignments will be tailored to each participant to match needs and resources, and include relevant background reading, research, participation in some or all livestreamed meetings and webinars, as well as the development of an action plan for implementation in their countries.

All participants will be expected to submit their monthly homework assignments before or by the last Monday of each month. The first assignment will be due 11 April, where participants are to provide a one-page summary introducing themselves, their position and organisation, their personal motivation and objectives for being in the Master Course, their preference for regular feedback (Group 1) or independent study (Group 2).

All participants are expected to attend the one-day, in-person workshop on October 31, 2016 at the World Cancer Congress in Paris.

**Course leaders:**
Dr. Sakari Karjalainen
Mrs. Roisin Foster
Dr. Wendy Yared

**Course faculty:**
Ms. Satu Lipponen
Mr. Luk Joossens
Dr. Sakari Karjalainen  
*President of the Association of European Cancer Leagues (ECL) and Secretary General of the Cancer Society of Finland*

Dr. Sakari Karjalainen is the President of the Association of European Cancer Leagues and Secretary General of the Cancer Society of Finland. He is also the Secretary General for the Cancer Foundation, the biggest private source of funding for cancer research in Finland. The Foundation provides about 4 million for research each year. The Society runs its own research institute, the Finnish Cancer Registry, which is a national, population-based registry. Karjalainen worked for the Cancer Registry after receiving his medical licentiate, in 1985, first as an epidemiologist and later as a senior researcher. His dissertation, published in 1991 was titled "Equity and Cancer "Patient Survival".

He is docent of epidemiology at Tampere University. Dr Karjalainen has previously been Director General of the Ministry of Education and Culture, where he led the Department of Education and Science Policy. Before joining the Ministry, Dr Karjalainen was Director of Health Research programmes at the Academy of Finland, the leading funding agency for primary research in Finland.

Ms. Roisin Foster  
*Chief Executive, Cancer Focus Northern Ireland*

Roisin Foster is the Chief Executive at Cancer Focus Northern Ireland since 2010. Roisin has over 30 years’ experience in the voluntary sector, including in disability (physical and learning). Roisin is also a Former Vice-Chairman and Chairman of the Southern Patients and Clients Council 1998-2004, former Board Member of the Childhood Fund (EU Funding Awarding Body); former Board Member of Oaklee Homes Group Care and Support Group; Member of NI Disability Appeals Tribunal (Quasi Judicial Appointment), a Board Member and Treasurer of ECL and member of UICC.

Roisin’s priorities as Chief Executive of Cancer Focus Northern Ireland has been to develop and management of all aspects of the work of Cancer Focus, which includes research, public policy, patient care services, cancer prevention/health promotion, marketing and appeals. Cancer Focus holds the secretariat for the Northern Ireland Assembly All Party Group on Cancer. Roisin has also led the rebranding and repositioning the organisation. Current lobbying/advocacy priorities and campaigns led by Roisin are around tobacco control, especially standardised packaging, equality of access to cancer drugs.

Dr. Wendy Yared, DrPH, MPH  
*Director, Association of European Cancer Leagues (ECL)*

Dr Wendy Yared is Director of the Association of European Cancer Leagues (ECL), a pan-European alliance of national and regional cancer leagues created in 1980. ECL facilitates the collaboration among cancer leagues throughout Europe and influence EU and pan-European policies by working closely with the European Commission and European Parliament. ECL provides the secretariat for the MEPs Against Cancer in the European Parliament. Dr Yared works with the Board toward ECL’s central purpose of identifying and promoting common strategies in cancer control, and toward achieving health equity in cancer prevention, treatment and services.
At the EU level, she is the Associated Partner of the current European Commission Joint Action in Cancer Control (Cancon 2014-2017) for dissemination. She was previously the leader for the Health Promotion and Prevention work package within the previous Joint Action Partnership for Action Against Cancer 2011-2014, led ECL to relaunch the European Week Against Cancer end of May, and to mobilise national organisations and local schools to participate in grass roots awareness-raising activities such as flash mobs and youth competitions for health promotion and cancer prevention and communicating the European Code Against Cancer. Dr Yared is active in the Commission’s Platform on Diet, Physical Activity and Health, as well as a founding member of the EU Alcohol and Health Dr Yared has more than 25 years’ experience in public health, most of which are in Europe.

She was previously with the World Health Organization, Regional Office for Europe. She was a consultant for the European Parliament; a public health researcher; a civil servant with the United States Public Health Service and is an advisor on international health systems and policy issues. She has also worked at the grassroots level in sub-Saharan Africa as a US Peace Corps Volunteer. An American from Los Angeles, her academic degrees are from the USA and include a Doctor of Public Health in International Health Systems from the Johns Hopkins University, a Master of Public Health in Health Policy from the University of California at Berkeley, and an undergraduate degree in psychology and biostatistics also from the University of California.

Ms. Satu Lipponen
Director, Communications and Foresight, Cancer Society of Finland and Managing Director, SyöpäCancer magazine

Satu Lipponen is director, communications and foresight, at the Cancer Society of Finland and managing editor of its magazine SyöpäCancer. She has been working for the Cancer Society since 2000. Before that she had a long career in journalism.

Ms Lipponen holds Master’s degree from the University of Tampere in international relations, economics and journalism. Satu Lipponen is member of global board of directors of the International Cancer Information Service Group ICISG and president of the European Science Journalists’ Associations EUSJA. Her detailed CV is on LinkedIn (linkedin.com/in/satulipponen)

Mr. Luk Joossens
Tobacco Control Advocacy Officer ECL and Belgian Foundation against Cancer

Luk Joossens is the Tobacco Control Officer at the Association of European Cancer Leagues and expert at the Foundation against Cancer (Belgium). Luk Joossens has been one of the world’s foremost tobacco control advocates for almost 30 years. In 2006, Luk was awarded a Luther L. Terry Award for his Exemplary Leadership in Tobacco Control. He is the author of more than 400 articles, reports, and presentations on various aspects of tobacco control.

Among other achievements, his pioneering work on Belgium’s tobacco advertising ban, European Union tobacco subsidies, and international tobacco smuggling has established him as an expert on tobacco control policy, a relentless activist, and a versatile leader in the international tobacco control movement.
Since 1994 Luk Joossens advised the World Bank, the European Commission, the World Health Organisation, the US Surgeon General, the Finnish government, the Belgian government, the UK Presidency, the International Union against Cancer, the Association of European Cancer Leagues, the Framework Convention Alliance and the Bloomberg Initiative to Reduce Tobacco Use about illicit tobacco trade. He represented Belgium in the International Conference on Illicit Tobacco Trade (ICITT) at the United Nations in New York City from July 30 to August 1, 2002 and made more than 100 presentations on illicit tobacco trade in 50 countries.

He was one of the rapporteurs of the WHO expert group on illicit tobacco trade, “Elaboration of a template for a protocol on illicit trade in tobacco products”, which was the discussion text during the first round of the negotiations on the illicit tobacco trade FCTC protocol in February 2008.

In 2015, Luk Joossens was awarded the WHO Director-General's Special Recognition Certificate for his outstanding contribution to tobacco control.