

## 4th IARC Cancer and Society Lecture

Friday 3 February 2017, 10h45 (Auditorium)

**Karin Holm, MBA**

President, Patient Advocates for Cancer Research & Treatment (PACRT)

**"Patient Power for Better Research: I can, We can"**

### Programme

10:45-11:00, Director's News

11:00-11:40, 4th IARC Cancer and Society Lecture

11:40-11:55, Questions session

11:55-12:00, Presentation of IARC Certificate

### Abstract

The diagnosis of cancer is undoubtedly a devastating moment in any person's life. However, more and more often, patients decide to take charge of their cancer experience by becoming informed patients, often supported by the cooperation and intelligence of other patients with similar cancers, patient groups, and Internet research. In this connected world where the Internet makes learning about cancer highly accessible, as empowered patients we can take responsibility to understand our conditions and options, share in decision-making, make our preferences known, and demand that our dignity and values are respected. We can mobilize to shape the cancer research and medical systems into directions that reflect our interests rather than those purely of the commercially driven medical community and pharmaceutical industry that thrive on perpetuating cancer growth. We patients will no longer be passive subjects of medical research or the big cancer machine.

This talk will share with IARC personnel the personal experiences of a breast cancer patient who has gone on to become a patient advocate for bringing the patient perspective into all areas of cancer research and clinical practice. She will expose the audience to ways in which some cancer research has been enhanced by closer collaboration with patients and patient groups. Reciprocally, she will pose the question of how cancer patients can better utilize and incorporate IARC's important findings on cancer causes and prevention so that the information can be better spread into the patient advocacy arena.

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In collaboration, patients and researchers like those at IARC, together can have a stronger impact on shaping approaches to cancer-free health across the world's societies and on standing on the side of healthy lives for all.

### Biosketch

Karin Holm is the founder of the Swiss non-profit association, Patient Advocates for Cancer Research and Treatment (PACRT), whose goal is to bring the patient perspective into all aspects of cancer research and treatment by placing informed patient advocates onto government research priority decision-making bodies, clinical trial design advisory committees, institutional review boards, research grant selection groups, and ethics commissions. [www.pacrt.org](http://www.pacrt.org)

Karin is a founding member of the Swiss European Union Patients' Academy on Therapeutic Innovation (EUPATI) national liaison team, in the French-speaking part of Switzerland. In 2015 she was appointed by the Geneva canton government to the Commission cantonale d'éthique de la recherche (CCER) to serve on the institutional review board for clinical research at the University Hospitals of Geneva (HUG) -- the first patient representative to do so in Switzerland. She is a co-investigator in a Swiss Cancer Research funded study to CO-create and pilot test a peer-led integrated Self-management program for breast cancer Survivors (COSS-study). [www.careum.ch/coss-study](http://www.careum.ch/coss-study)

A breast cancer survivor, Karin was also a carer for her late mother who died following surgery for pancreatic cancer.

In her professional life, she works for the Council for International Organizations of Medical Sciences (CIOMS) in Geneva, Switzerland, as technical collaboration coordinator for CIOMS which is a think tank organizing multi-stakeholder expert working groups on topics concerning pharmacovigilance/drug and vaccine safety and bioethics. ([www.cioms.ch](http://www.cioms.ch))

Previously Karin held positions in or consulted to the World Health Organization, Global Forum for Health Research, Initiative on Public-Private Partnerships for Health, and International Federation of Pharmaceutical Manufacturers and Associations in the area of public-private partnerships in global health. She earned a Master of Business Administration (MBA) from the Tuck School at Dartmouth College, in New Hampshire, USA and a bachelor's degree from Dickinson College in Pennsylvania, USA.