



*The Nordic Cancer Union and the Scientific Committee in joint meeting on the Faroe Islands, October 2014*

# Annual Report 2014

## *The Nordic Cancer Union*



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Nordic Cancer Union  
[www.ncu.nu](http://www.ncu.nu)

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For individual medical questions, we encourage you to contact directly the NCU member league in your country.

# NCU

## *in short*

The Nordic Cancer Union (NCU) was founded in 1949. It is a collaborative body consisting of members from the Danish, Swedish, Finnish, Icelandic, Norwegian, and Faroese Cancer Societies. The Åland Cancer Society holds an observer status in the NCU. The NCU secretariat for the years 2009-2011 was chaired by the Swedish Cancer Society. The NCU secretariat for the years 2012-2014 was chaired by the Faroese Cancer Society. The chairman was Jákup N. Olsen. The NCU secretariat for the years 2015-2017 is chaired by the Icelandic Cancer Society. The chairman is Ragnheiður Haraldsdóttir.

The goal of the NCU is to collectively improve understanding of cancer diseases, find effective prevention, obtain and further results of cancer treatment and rehabilitation as well as enhance their effective application in the Nordic region.

The Nordic Cancer Union is governed by a Board comprising the Secretary Generals of the NCU member organisations. The Board has 3-4 annual meetings to coordinate joint activities.

These regular meetings enable and facilitate information exchange about ongoing campaigns, activities, discussions and other processes at national levels while developments are followed-up and discussed. An important part of NCU collaboration is to encourage joint cancer research of qualitative standards within the Nordic research community.

The Secretariat is responsible for general administration and coordination of NCU activities. Coordinator of the NCU Secretariat for 2012-2015 is Birita Ludvíksdóttir, legal adviser. The secretariat concerning grant management is permanently located at the Norwegian Cancer Society, and the coordinator for this part of the secretariat is Elisabeth Støve, special consultant.

In 2014 the Faroese Cancer Society has coordinated the activities in NCU and has arranged 3 NCU meetings. The general assembly was held in Copenhagen in May 2014. Apart from this another meeting was held in Copenhagen in February 2014, and a meeting was held in the Faroe Islands in October 2014. The NCU Scientific Committee also held a meeting in the Faroe Islands in October 2014, which was partly held as a joint meeting with the NCU.

### ***NCU towards closer cooperation with the Nordic Council and the Nordic Council of Ministers***

On the 30th of October 2013 the Nordic Council adopted the resolution concerning focus on long-term perspectives on cancer in the Nordic countries and cooperation between the NCU, the Nordic Council and the Nordic Council of Ministers on initiatives launched by the Nordic Cancer Union.

This was one of the great achievements of NCU cooperation in 2013, due to hard work in 2012 and 2013. The NCU was very pleased that the resolution was adopted, and focused in

2014 on getting the resolution implemented in the Nordic Council of Ministers and in the health policies in each Nordic country.

In January 2014 the Westnordic Health Ministers and Bo Kønberg, former health minister and governor in Sweden, had a meeting in the Faroe Islands, where the NCU chairman was invited to have a presentation on the NCU and benefits of strengthening nordic cooperation in the field of cancer.

In April 2014 the Danish Cancer Society had a meeting with the secretariat of the Nordic Council of Ministers, where the benefits of nordic cooperation in the field of cancer were discussed. NCU recommended the Nordic Council of Ministers to focus on strengthening register research, specialized cancer care in the Nordic countries, a joint Nordic research education and joint Nordic clinical studies. The secretariat was positive towards a strengthened cooperation with the NCU.

After the meeting NCU sent its contribution to Bo Kønberg's report on how nordic cooperation on health can be improved and strengthened over the next 5-10 years. Bo Kønberg delivered his report to the Nordic Council of Minister's meeting on Iceland in June 2014. In connection with the report, representatives from the NCU were at a meeting with the Nordic Council concerning future cooperation on the field of cancer. The report is a step in the right direction concerning a joint nordic effort on cancer treatment and research in the Nordic countries.

The NCU is delighted that the organisation has succeeded in getting a closer cooperation with the Nordic Council and hopefully also with the Nordic Council of Ministers in the close future.

# NCU Approved Research Grants 2014

## *The Scientific Committee*

The scientific committee comprises one member with scientific competence from each member country appointed by the NCU Board after recommendations from the national cancer societies.

Members of the Scientific Committee 2012-2014 were: from the Faroe Islands: Johan Poulsen, chairman of the committee, physician and urologist, from Denmark: Elsebeth Lyng, professor and mag.scient.soc, from Finland: Jorma Keski-Oja, professor, from Sweden: Eva Hellström Lindberg, Professor, physician and researcher, from Norway: Kristina Kjørheim, Chief and Deputy Head of Department for Research in Cancer Registry, and from Iceland: Asgerður Sverrisdóttir, consultant and employee of "Landspítali" in Iceland.

The scientific committee is invited to an annual meeting and members from the committee to the meeting for the Committee of Representatives held every third year.

The tasks of the committee are to assess scientific grant applications, secure high scientific quality and formulate recommendations regarding the applications to the Secretaries-General for their decisions on grants, to give consultation concerning strategic projects regarding research to the Secretaries-General for their decisions on grants, and to evaluate funded research and follow-up on the application of the results in the Nordic countries. Each year 750.000 euros are granted for cancer research. The secretariat of the committee is permanently located at the Norwegian Cancer Society.

The NCU has been awarding research grants since 1989. Applications are handled in two phases: beginning with the national expert groups and then by the Nordic Research Committee which comprises one representative from each NCU member country.

The Nordic Cancer Union received 35 grant applications in 2014. 15 of these applications were accepted, and received the 750.000 euro. The annual NCU Scientific Committee meeting was conducted on the Faroe Islands on October 10, 2014. The committee's assessment is based on quality, level of Nordic synergy, and relevance to NCU's strategy.

## *Awarded NCU Research Grants 2014*

<b>Principal Investigator</b>	<b>Project Title</b>	<b>Project workplace (Principal Investigator)</b>	<b>Awarded amount (Euros)</b>
Abildgaard, Niels	Prolonged Bone Protection in Multiple Myeloma - the Magnolia Study	Odense University Hospital, Denmark	50.000
Bjørge, Tone	Pregnancy characteristics and maternal cancer: A joint Nordic study	University of Bergen, Norway	30.000
Brown, Peter de Nully (Nordic Lymphoma Group)	Biomarker-driven, risk-adapted trials in aggressive lymphomas and Hodgkin lymphoma	Rigshospitalet, Denmark	40.000
Dillner, Joakim	Optimisation of HPV-based cancer control strategies	Karolinska Institute, Sweden	50.000
Fuxe, Jonas	Exploring immune cell properties of cancer cells as an early sign of metastasis in Swedish and Finnish breast cancer patients	Karolinska Institutet, Sweden	50.000
Grotmol, Tom	Association between gene variation and the response to chemotherapy for testicular cancer - clinical outcomes and adverse effects	Cancer Registry of Norway, Norway	50.000
Hellström Lindberg, Eva	Nordic MDS Group (NMDSG) Clinical Trial program and new biobank and molecular platform to improve outcome for patients with MDS	Karolinska Institute, Sweden	50.000
Herrstedt, Jørn	EWOC-1 (Elderly Women Ovarian Cancer) Trial	Odense University Hospital, Denmark	50.000
Hägglund, Hans	Potential hazards for hematopoietic stem cell donors	Uppsala University Hospital, Sweden	40.000
Jönsson, Göran	Molecular epidemiology of familial ocular and cutaneous malignant melanoma; a Swedish-Danish collaboration	Lund University, Sweden	50.000
Kjærheim, Kristina	Lifestyle and occupational cancer risk - adjusting for alcohol and tobacco	Cancer Registry of Norway, Norway	60.000
Lagergren, Jesper	Influence of obesity surgery on cancer risk in a Nordic population-based cohort study	Karolinska Institutet, Sweden	50.000
Mustjoki, Satu	The nordic CML study group: Immunological	Helsinki University Central	70.000

	evaluation of factors related to the successful therapy discontinuation	Hospital Cancer Center, Finland	
Nordin, Karin	Phys-Can. Physical training and cancer	Uppsala University, Sweden	50.000
Peltomäki, Päivi	Search for novel high-penetrance susceptibility genes for familial cancer from Finnish and Danish cohorts	University of Helsinki, Finland	60.000
<b>Total</b>			<b>750.000</b>

# Strategic Funds

The Nordic Cancer Union provides funding to support and stimulate collaborative cancer research within the Nordic countries. Researchers working in two Nordic countries or more must be involved in the project. The research projects must have cancer relevance, be uniquely suited to be carried out within the Nordic countries, and the effect of collaboration should be synergistic.

Strategic projects derive from the needs of cancer societies in defining future political initiatives. Funding for other strategic projects and initiatives will be considered with increased emphasis on the quality and evaluation of the projects.

Special emphasis in this area is given to research-related projects like monitoring, documentation and analysis of data. Knowledge and documentation on cancer diseases (e.g. cancer incidence and mortality, survival after a cancer diagnosis) in each individual country identifies fields in which improvements are needed. Comparisons between the Nordic Countries are extremely essential for the work on cancer programmes, including the prioritising of the efforts.

Developments are taking place continuously with regard to diagnostic and treatment issues. The gathering of data, analysis and evaluation of these developments provide essential knowledge for improving results of cancer prevention, treatment, rehabilitation and palliative care. Continuous monitoring and evaluation also raise media attention in the field. Strategic projects and issues can also include the training of researchers as well as other projects on problems of current interest that are essential to cancer control.

## **Strategic projects**

In the period 2012-2014 NCU has financed the following strategic projects.

- Nordic Summer School in Cancer Epidemiology in 2014
- IARC Summer School
- NORDCAN
- "Safety on Sun Holidays"
- Nordic Melanoma Meeting in Oslo, 2012.



# The Danish Cancer Society

## *Kræftens Bekæmpelse*

**Managing Director**                      **Leif Vestergaard Pedersen**  
**President of the Board**                **Frede Olesen, Professor, Dr. Med. Sci.**

### **Structure of the Organisation**

The Danish Cancer Society was founded in 1928 and is a democratic organization with more than 266.000 members. The members are organized in 98 local committees. The committee members are elected at the annual general meeting. The 98 local committees constitute the governing body of the Danish Cancer Society meeting once a year.

In each of the 5 regions a regional committee has been set up. Both local and regional committees cooperate with the local and regional administrations.

652 people are employed by the Danish Cancer Society within research, patient support and prevention/information. The number of volunteers are app. 42.400 including participants in the annual door knocking campaign.

### **Income and Costs**

As far as concerns fundraising and income in 2014 was a successful year. The Danish Cancer Society's income was 87.109.000 euros. Gifts accounted for 60.401.000 euros, legacies for 19.274.000 euros, subsidies for 3.564.000 euros and others accounted for 3.869.000 euros.

Total operating costs (staff included) were 95.013.000 euros.

In 2014, the Danish Cancer Society distributed costs on the following target areas: Research 54.291.000 euros, prevention: 12.655.000 euros, cancer patients care: 18.575.000 euros and other activities: 9.492.000 euros.

### **Political achievement: all patients will be entitled to a personal specialist to co-ordinate the entire patient journey**

In a specialised health care system, cancer patients are very often admitted to a lot of different wards and hospitals with no doctors having a specific role or responsibility for the entire patient journey. This makes patients, families as well as health professionals uncomfortable and frustrated and in worse cases, patients experience safety hazards when the responsibility is shifting.

During 2014, The Danish Cancer Society has worked hard to get the authorities and the medical associations to indorse an introduction of a personal specialist. In 2015, the regional

health authorities have finally announced that from the year 2018 all patients admitted to a hospital will be offered a personal specialist, who makes sure that the patient is involved in his or her treatment, coordinates the treatment and avoid unnecessary waits.

### **The Danish Cancer Society Research Center (DCRC)**

The Danish Cancer Society Research Center (DCRC) was established on 1 January 2012 as a merger between the Institutes of Cancer Biology and Cancer Epidemiology. The Center, which holds a dynamic, international and competitive research environment spanning basic, translational, epidemiological and clinical aspects, employs some 200 researchers and technicians and a varying number of scholars and guest researchers. The DCRC is furnished with modern office facilities, fully equipped laboratory space including access to state-of-the-art machinery and animal house.

The scientific work of DCRC is organized into eight research units and one junior group:

*Diet, Genes and Environment* headed by prof. Anne Tjønneland, *Virus, Lifestyle and Genes* headed by prof. Susanne Krüger Kjær, *Cell Death and Metabolism* headed by prof. Marja Jäättelä, *Genomic Integrity* headed prof. Jiri Bartek, *Survivorship (SVP)* headed by prof. Christoffer Johansen, *Cell Stress and Survival* headed by prof. Francesco Cecconi, *Translational Cancer Research* headed by prof. Nils Brünner, and *Statistics, Bioinformatic and Registers* headed by chief statistician Klaus Kaae Andersen. In addition, the Center holds a junior group headed by Petra Hamerlik, which works under the theme *Brain Tumor Biology*.

The Center is headed by prof. Jørgen H. Olsen.

In 2014 two major research initiatives were undertaken by the Center Management:

The “*Diet, Cancer and Health*” cohort first established in the mid-1990ies and holding epidemiological data, physical measurements and biological samples on 57.000 Danish citizens will be extended with similar information on biological children and grandchildren of the initial cohort members and forming “*Diet, Cancer and Health – Next Generations*”. Over the coming 2½ years register data will be acquired on 88,000 children, 64,000 spouses of the children, and 128,000 grandchildren, and a large subsample of 145,000 individuals will be invited to participate in a baseline examination and collection of biological material. The resulting three-generation cohort will allow in-depth trans-generational studies of the role of genetic, epigenetic, microbiomic, environmental and socio-economic factors and their complex interactions in the pathogenesis of cancer and other chronic and sub-chronic diseases. Similarly, the extended cohort will constitute a unique resource for studies of biomarkers predicting such disorders.

The second major initiative was the establishment of a new Center within DCRC, i.e. *Center for Autophagy, Recycling and Disease (CARD)*. This center, which is headed by prof. Marja Jäättelä, is established as a structural, cross-center and cross-disciplinary collaboration between researchers from three DCRC Units, i.e. *Cell Death and Metabolism*, *Cell Stress and Survival* and *Genomic Integrity*. The task of the new center is to describe the machinery behind maintenance, renovation, and recycling of the various components of the cell. This machinery keeps a sharp watch on the daily ‘cleaning’ of the normal cell; however, it also helps malignant cells to survive by removing chemotherapeutic agents and intracellular structures destroyed by radiation therapy. The overall aim of the new center is to answer the

question: How can this cellular machinery be used in the treatment and prevention of cancer? The center is made possible due to a large grant from the Danish National Research Foundation.

The scientific output from DCRC in 2014 was summarized in 251 papers published in the international peer reviewed literature. A full list of publications is accessible using the following link:

<http://www.cancer.dk/research>

### **Documentation & Quality**

Documentation & Quality (DKV) was established in April 2014 by merging the department of Quality & Safety with the Documentation Unit. DKV in the Danish Cancer Society was set up to monitor and improve Danish cancer care with valid and comprehensive data. Our research involves (clinical) epidemiology, strategic data management, health services research and medical improvement sciences.

DKV activities include:

- Publications on adverse events registered in the Danish Patient Safety Database (inadequate information sharing and liability, diagnostic delay, medication errors, and insufficient palliative care).
- Research on patient safety in cancer surgery, a joint project between the Danish Cancer Society and the Danish Multidisciplinary Cancer Groups.
- Adding activity and comprehensive quality data to the current Danish Cancer Registry, i.e. Danish Cancer Registry version 2.0.
- Policy decision on and implementation of one responsible doctor in each patient pathway.
- Launch of a national model to recruit and educate volunteers in supporting social vulnerable cancer patients (Patient Navigators).
- Forecast of the incidence and prevalence of cancer until year 2025, and associated care needs.
- Several projects regarding implementation of PROMS (Patient Reported Outcome Measures) at 11 hospital departments (lung- and prostate cancer).
- Danish version of PRO-CTCAE (Patient Reported Side Effects of Chemotherapy) jointly by the Oncology Clinic at the Copenhagen University Hospital, the Danish Cancer Society, and the National Cancer Institute, USA.
- National survey of young cancer patients' needs and experiences with cancer care provided by the Danish healthcare system.
- NORDCAN updated to 2012 including regional data for all Nordic countries. Cancer survival for patients diagnosed 2009-2012 was added in the December 2014 update.
- Danish data included in the European Cancer Observatory database, EUREG, 1978-2007.
- Strategic research on cancer mortality factors jointly with DMCG. Project investigating possible factors influencing death among cancer patients.
- Enhanced monitoring of Danish cancer care, including patient safety, patient centred cancer care and waiting times.
- Strategic partnership with Lillebaelt Hospital (Central Denmark Region) around a Centre for Shared Decision Making in cancer care.

- Development of a national survey concerning cancer patients' needs and experiences with the Danish healthcare system.
- Proactively lobbying to increase shared decision-making and patient centred care in Danish cancer care.

### **Patient Support & Community Activities**

The Danish Cancer Society is in the last phase of building seven modern counselling centres in the vicinity of the large oncology centres in Denmark. The counselling centres are following a new concept combining modern architecture and counselling services with focus on empowerment of patients. Four new counselling centres, designed by young Danish architects, opened in 2013 and in 2014 another two centres opened and have created new opportunities for helping cancer patients early after diagnosis, and helped establishing new collaboration with the hospital staff. The centres offer information, psychosocial support from professionals, support groups, exercise etc. Among new activities are physical training sessions for cancer patients during treatment as part of early rehabilitation and mindfulness meditation. In 2014, a pilot project was initiated to promote video transmitted counselling in two counselling centres. In order to make activities in the counselling centres more transparent, concepts for activities were agreed on, based on the best possible evidence.

In 2012 a new strategy for patient support was approved focusing on empowerment of users, the involvement of volunteers in patient support activities, support to families, and more focus on, how to reach new target groups such as men, ethnic minorities and socially vulnerable users. In 2014, a major project was implemented at a counselling centre to offer support and social networks for men with cancer and to integrate gender sensibility into the counselling activities. Based on this, specific activities for men will be offered all over Denmark. In 2014 in another national project, the Navigator project, volunteers were educated to support socially vulnerable cancer patients during treatment and rehabilitation. This project will be further expanded all over Denmark in 2015.

Also in 2014 the focus on how to support young cancer patients was further intensified.

In 2014, the helpline 'Kræftlinjen' focused on further expanding online counselling and the social network Cancerforum, which resulted in an increased number of users besides telephone counselling. In a large project 'OmSorg' works to promote peer groups at schools for children, who have lost a parent. In 2014, OmSorg was shareholder in a large project to promote awareness about communication with children when a parent has cancer.

Patient Support & Community Activities also focused on social rights for cancer patients in 2014, and a number of issues such as the right to take leave during cancer in the family, insurance issues and other juridical issues were brought to attention.

Patient Support and Community Activities has a widespread local organisation all over Denmark and support the implementation of rehabilitation and palliative care activities in Danish municipalities and the implementation of a report on a generic clinical pathway for rehabilitation and palliative care after cancer. In 2014 a national working group on cancer rehabilitation was established and reported on how to promote evidence based cancer rehabilitation in Denmark

## **Cancer Prevention & Information**

### **Smoking:**

As the largest single preventable cause of cancer, smoking is a key area of work for the Danish Cancer Society. We are committed to reduce smoking rates and to promote smoke-free environments.

Although high on the agenda, the proportion of daily smokers in Denmark did not decrease in 2014.

At the end of 2014, 21 % of all adults (15+) smoke and 17 % smoke on a daily basis. 5 % smoke e-cigarettes and 74 % of those who smoke e-cigarettes also smoke conventional cigarettes (dual users).

Smoke-free environments are increasing, at present 70 % have a totally smoke-free home and 84 % of the employees work in a smoke-free indoor environment.

The Danish Cancer Society's "Healthy Together" programme helps workplaces to introduce 'smoke-free working time' and from 2013 to 2014, the fraction of employees having 'smoke-free working time' increased from 8 % to 15 %. 'Smoke-free working time' supports smoking cessation, avoids smoking start and protects employees from tobacco smoke exposure inside and outside. Moreover, 'smoke-free working time' removes visibility of smoking, which is important to prevent new generations from smoking and help people planning to stop smoking. 'Smoke-free working time' has also proven to be an effective means to initiate the process of obtaining a smoke-free working environment for employees in nursing homes and psychiatric units. Employees in these sectors are exposed to indoor tobacco smoke from residents, and the smoke-free work hours of the employees help facilitate a dialogue with the residents about their indoor smoking.

The "Clear the air" campaign focuses on the 33 % of those living in blocks of flats that are exposed to the neighbours' tobacco smoke in own apartment starting a new partnership to achieve more smoke-free multi-unit housing in Denmark. Furthermore, we are working to reduce the amount of pregnant women smoking as well as their babies' exposure to tobacco smoke. The introduction of electronic cigarettes in the market poses a new challenge to tobacco control and prevention. We follow the science and inform health personnel about facts and dilemmas at seminars. Currently new Danish legislation is underway, according to which e-cigarettes will probably be subject to the same regulation as tobacco concerning smoke-free environments, advertising, and an age-limit of 18 years.

In the area of smoking prevention and cessation help for children and adolescents, we have an extensive collaboration with Norway and Sweden. X:IT in Denmark ([www.XIT-web.dk](http://www.XIT-web.dk)), a program to prevent the start of using tobacco among students in secondary school, is developed in connection with the initiatives of the municipalities, rules at the schools, the education, and contracts with the parents and based on the good experience from Norway and Sweden. Our digital smoking cessation program ([www.xhale.dk](http://www.xhale.dk)) for adolescents is also used in Norway and Sweden.

In 2014 we have launched e-kvit, the digital smoking cessation program for adults for individual application. E-kvit is a flexible offer of support in the cessation period with daily videos, text messages, discussion groups etc.

### **Campaigns about symptoms of colon cancer and prostate cancer:**

Men have a higher incidence and mortality of cancer than women. One reason is that men tend to ignore the symptoms and/or wait to see if things get better before seeing their GP.

In 2014 the Danish Cancer Society launched "Hold øje, mand!" two campaigns about symptoms of colon cancer and prostate cancer aimed at men aged 50-75, using humour and well-known Danish men talking about symptoms of colon and prostate cancer in the most obvious setting – the toilet – [www.holdojemand.dk](http://www.holdojemand.dk). Both types of cancer are more or less tabooed. The campaigns worked with these taboos, stressing that the possibility of recovery is good if you see your GP in time. Both campaigns have been well received by the target group and have increased the knowledge about symptoms among the target group as well as the willingness to react on symptoms.

### **Campaign about symptoms of cancer – the 7 signs of cancer:**

The Danish Cancer Society works to diminish social inequality in health and patient delay. Danish cancer patients have a lower survival rate than e.g. cancer patients in Norway and Sweden. One of the reasons is that more Danish cancer patients are diagnosed in later stages, which makes treatment difficult. Studies show variation in the knowledge of symptoms and that knowledge is lowest among men and people with low education.

In 2014 we have been preparing a campaign named "De 7 tegn" aimed at motivating the Danes to be aware of specific cancer symptoms and to talk to their GP about symptoms that might be signs of cancer.

### **Physical activity and diet:**

By means of external funding, we have completed the first round of the project "Leg på streg", where 25,000 young schoolchildren had the possibility of learning math and Danish language while being physically active in hopscotch squares in schoolyards in all parts of the country.

We have published a review establishing the scientific evidence on the effectiveness of calorie labelling in fast food outlets, which can be accessed from our website. In collaboration with the industry, NGOs and food authorities, we have developed recommendations for a simple, safe and comprehensible implementation of calorie labels in fast food outlets, cafés and kiosks.

### **Prevention of skin cancer:**

The Danish Cancer Society has continued its Sun Smart campaign. This year, the strong focus was on communicating the benefits of 'seeking shade' in the natural sun and with a high attention rate to our message of "skyggehygge". Furthermore, we have continued our network with Nordic partners on the various issues of sun protection.

### **Prevention of alcohol-related cancer:**

The Danish Cancer Society has established a new initiative called "Fuld af liv" in order to prevent alcohol related cancer. The campaign aims at reducing alcohol consumption among kids, teenagers and young adults – and to postpone the alcohol debut among young Danes.

The first campaign initiative in the fall of 2014 was targeted at young people aged 15-25. It achieved 46 % recognition in the target group and an overwhelming majority of positive attitudes towards the campaign and the campaign messages.

A full list of publications from Cancer Prevention & Information is accessible using the following link:

<http://www.cancer.dk/om-os/organisation/forebyggelse-oplysning/publikationer-2014/>

# The Cancer Society of Finland

## *Cancerforeningen i Finland*

**Secretary General  
Chairman**

**Dr. Sakari Karjalainen  
Professor Teuvo Tammela**

### **Structure**

The Cancer Society of Finland, CSF, founded in 1936, is a national umbrella organisation comprising 17 member organisations (12 regional societies and five national patient organisations). The CSF maintains the Finnish Cancer Registry and handles the administrative duties of the Finnish Cancer Foundation. It has one laboratory and, through its member organisations, provides health care services. It runs counselling services nationally and regionally that offer psychosocial support to patients, their relatives and friends, professionals and all those interested in cancer.

Number of employees: 89 at the CSF and 160 in the member organisations. Several hundred people work for the organisation as volunteers.

The main fields of activity of the CSF include health promotion, counselling, cancer control, research, rehabilitation and recreation for cancer patients, palliative care, peer support, volunteering for cancer activities, cancer epidemiology and screening (quality assurance, research and planning) and communications (magazines, leaflets and internet).

### **Income**

The income of the Society was 9.378.000 euros in 2014. Biggest sources of income were laboratory 1.767.000, subsidies 1.607.000 and fundraising 1.022.000.

Total operating costs (staff included) were 8.865.800 euros.

In 2014, the Society distributed costs on the following target areas: cancer registration, mass screening registration and research 2.967.000 euros, laboratory 1.731.000 euros, health promotion 1.412.000 euros and communications (including Syöpä-Cancer magazine) 795.000 euros and rehabilitation 488.000 euros.

### **Highlights of activities in 2014**

The focus of activities included actively influencing national cancer policy, boosting activity directed at CSF members and increasing membership, and developing the quality of performance and services.



New strategy for the Cancer Society, including the Finnish Cancer Registry and Cancer Foundation, was approved in December 2014. The operational concept of the Society is beating cancer. Values of the work are equality and justice, reliability, availability and sense of community. Vision statement is: A good life without cancer and despite cancer. Five strategic aims identified are: strengthening cancer prevention and early detection, supporting the development of cancer treatment, promoting good quality of life despite cancer, strengthening cancer research and strong, proficient organization in a changing world.

It has been possible to strengthen the operating conditions of member associations in arranging advisory services and patient support, due to support from the Cancer Foundation. Work continued in 2014 to improve the effectiveness of operations, reduce expenses and ensure the appropriate allocation of resources.

### **Advocacy and public relations**

In line with its rules, the Finnish Cancer Society aims to prevent the destructive effects that cancer results for people in Finland. Apart from health promotion, advisory work, rehabilitation, communications and research, CSF tries to further this aim by influencing policy decisions at national and EU levels and in international structures.

CSF representatives took an active part in governmental working groups, such as in the Ministry of Social Affairs and Health (MSAH) Screening Group. The Ministry proposed in 2014 that a national Comprehensive Cancer Centre should be established. CSF supported this aim and its experts were actively advocating for the Comprehensive Cancer Centre.

CSF representatives were playing an important role in the cancer experts' group established by the National Institute for Health and Welfare. The second phase of the National Cancer Control Plan was published in May 2014. The plan deals with improving cancer prevention and health promotion, guidelines on early diagnosis and cancer screening, rehabilitation support for cancer patients, and boosting related training and research.

From the initiative of the CSF of a national branch of the non-communicable disease network, the NCD Alliance of Finland was founded and the CSF was chairing the Alliance.

### **Member organisations**

The CSF with its 12 regional and five patient societies had 123 937 members at the end of the year 2014. The biggest regional organisation is the Cancer Society of South-Western Finland with nearly 30 000 members. Member associations had about 180 local branches or clubs.

Regional cancer societies cover the entire country, as far as the Åland Islands. In 2014 each societies has at least one office providing counselling by an experienced nurse. The core activities of all regional societies involve counselling for patients and relatives, as well as peer support.

National patient organisations operate nationwide and collaborate with the regional societies and the CSF.

### **Counselling services**

Counselling services providing psychosocial support constitute one of the most important tasks of the CSF. Membership organisations play a vital role in counselling.

The CSF's national counselling services have had as its staff 6 nurses and 2 medical doctors in 2014. There were 50 nurses working for cancer organisations. Counselling services are available for everyone affected or concerned by cancer-related matters. The objective is to provide information and psychosocial support to cancer patients, their relatives and others who are worried about cancer. Counselling is done face-to-face or at group meetings, via telephone or online chat. Chat and group chat are in Finnish, but in 2014, this service was extended to include Swedish.

The nationwide counselling service received about 4.500 contacts, 75% of them by phone and 25% by email.

In 2014 CSF launched a new counselling helpline specialising in pain. This was done in collaboration with the Helsinki University Hospital Clinic in Helsinki. Legal and social benefit counselling continued to its 2<sup>nd</sup> year. The aim is to complement other counselling services with telephone help about patients' rights and their financial situation.

### **Health promotion and tobacco control**

On health promotion, the CSF coordinates a national programme aimed to reduce tobacco use among young people. One of the successes was [www.tobaccobody.fi](http://www.tobaccobody.fi) which raised international interest. In 2014 a new video Breath Holder focusing on passive smoking and children was released on YouTube. Collaboration with smoking prevention in the Defense Force continued. Health promotion themes also included campaigning on sun exposure, and nutrition, exercise and weight management. Rehabilitation, peer support and recreational courses are a part of the work of the CSF.

### **Finnish Cancer Registry**

The Finnish Cancer Registry plays an important role in producing information on national cancer policy. It maintains a database of all cases of cancer in Finland and functions as statistical and epidemiological research institution. The Mass Screening Registry is a branch of the Cancer Registry, and it maintains a database on the cancer-screening programme, and plans and evaluates national cancer screening. The information generated by the two registries is used for producing statistics in cancer and screening, cancer research and to support health policymaking.

The Cancer Society of Finland provides the basic funding for the Finnish Cancer Registry. The National Institute for Health and Welfare (THL) has made a contract with the Cancer Society for the practical organisation of the registry's activities (including mass screening registries) and partially funds the cancer register. Research projects are usually funded with grants from national and international sources.

### **Communications**

The themes of CFS communications in 2014 were fundraising, cancer research and preventing smoking and the use of tobacco products. The main online is website [www.cancer.fi](http://www.cancer.fi), which had 1.7 million visitors. In 2014 developing more mobile friendly webpages started. Other information channels included the Syöpä-Cancer magazine, Facebook and Twitter.

Swedish language and more detailed version of the CSF main activities in 2014 is available on the Internet <http://www.cancer.fi/se/cancerorganisationerna/verksamhet/verksamhetsplan/>

# The Faroese Cancer Society

## *Krabbameinsfelagið*

**Director**                                      **Jansy Gaardlykke**  
**Chairman of the Board**                **Jákup N. Olsen**

### **Structure**

The Faroese Cancer Society was founded in 1979 with the purpose to address the challenges of cancer in the Faroe Islands. The society is governed by a board of five members, which is elected at the annual General Assembly. The main office is situated in the capital: Tórshavn. Two employees are employed at the office. A psychologist and a social worker are also affiliated with the society. The number of volunteers are app. 40 people.

### **Income**

The Faroese Cancer Society's total income in 2014 was 167.779 euros. Gifts accounted for 107.855 euros and others accounted for 59.924 euros.

Total operating costs (staff included) were 168.724 euros.

In 2014, the Faroese Cancer Society distributed costs on the following areas: Prevention: 7.581 euros, cancer/patients care: 10.888 euros, research: 5.333 euros and on other activities: 2.552 euros.

### **Activities in 2014**

The Faroese Cancer Society and its group activities grow forth. More and more patients, relatives and others seek our consulting.

In addition to a wide variety of offers to cancer patients and their relatives, the Society keeps up with what is happening in the cancer field in the Faroe Islands and in the countries around us. An important task is to influence the authorities to improve their services and offers to cancer patients.

### **The NCU presidency**

In 2011, Jákup N. Olsen, chairman of the Faroese Cancer Society, was elected chairman of the Nordic Cancer Union. In 2014 the Faroese Cancer Society has coordinated the activities in NCU and has arranged 3 NCU meetings. The general assembly was held in Copenhagen in May 2014. Apart from this another meeting was held in Copenhagen in february 2014, and a meeting was held in the Faroe Islands in October 2014. The NCU Scientific Committee also held a meeting in the Faroe Islands in October 2014, which was partly held as a joint meeting

with the NCU. Coordinator of the NCU Secretariat for 2012-2014 is Birita Ludvíksdóttir, legal adviser.

### **Bicycle for children with cancer**

Team Rynkeby has activities in Finland, Norway, Sweden, Australia and in Denmark. In 2013 an agreement was made between Team Rynkeby, The Children's Cancer Fund and the Faroese Cancer Society to bicycle to Paris in July 2014. The activity: "Bicycle for children with cancer" proved to be very successful. Many people participated and among the participants was the prime minister of the Faroe Islands. The income of this activity goes to children with cancer.

### **Activities of Help groups**

#### **The Prostate Cancer Group**

The group has had many fruitful meetings in 2014. In January 2014 the group assembled 250 men for a lecture on "Men and cancer", where no women were allowed. The group's purpose is for men to get together to chat and support each other, to gather knowledge on prostate cancer, to inform on prevention and to arrange different events.

#### **The Breast Cancer Group**

Self help group "Bót til Bata" wants to reach as many women, who have undergone surgery for breast cancer, as possible. In 2014 the group arranged several meetings and lectures on the subject breast cancer.

#### **The Pelvic Cancer Group**

The group has arranged courses and gatherings for people, who suffer from pelvic cancer.

#### **The Melanoma Group**

The group met regularly for conversation, lectures and cozy togetherness. The group continues to gather knowledge on melanoma in order to provide information better on how to prevent skin cancer and melanoma.

#### **The Stoma Group**

Together with the central hospital, the group has arranged courses and gatherings for people, who suffer from stoma.

#### **Parents Group**

The Parents Group organised a Christmas party for families of children with cancer in December 2014.

### **Conversation groups**

The Society is constantly trying to adapt the offers to the needs of patients and relatives. Conversation groups have been arranged for people, who have lost spouses to cancer and groups for relatives, groups for children, whose parents suffer from cancer and also offer talk therapy to families with children where one parent is suffering from cancer. As a new issue the Society has started a group were parents, who have lost adult children to cancer, meet. The aim of these groups is that you meet people in the same situation as yourself and you can get help from talking to each other.

### **Statistics**

In 2014, 207 new cases of cancer were diagnosed in the Faroe Islands. Almost one in five,

who are diagnosed with cancer in the Faroe Islands, get skin cancer. The number of people, who got skin cancer, was 22 in 2011, and was 49 in 2014. On the other hand, the number of melanoma cancer decreased from 16 cases in 2005, to 2 cases in the past year. Breast cancer between women, which is the most common form of cancer, is fairly stable. The past seven years, there have been between 20 and 25 cases per year. Lung cancer is among the most common forms of cancer. Every year, between 10 and 15 people in the Faroe Islands get lung cancer. This figure is also pretty stable. It was a great achievement that the Faroese cancer statistics was registered in NORDCAN. Now you can take the Faroese figures out and compare them with those of the other Nordic countries.

# The Icelandic Cancer Society

## *Krabbameinsfélag Íslands*

**Director**  
**Chairperson**

**Ragnheiður Haraldsdóttir**  
**Jakob S. Jóhannsson**

### **Structure**

The Icelandic Cancer Society (ICS) was established in June 1951. The ICS is an umbrella organization of 34 member associations (24 local associations around the countryside and 10 support groups). At the Annual General Assembly, seven members are elected to the governing board of the Icelandic Cancer Society. The Board meets regularly every month. The Chairmen of the various member cancer associations convene as a rule in the autumn, often outside the capital area.

The ICS has a remarkable history and has through the decades concentrated its engagement on prevention (e.g.cancer detection), education, research and patient services.

Based on a service contract with the Ministry of Welfare, the ICS runs a countrywide mammary and cervical cancer screening programs and has done so for decades. The Icelandic Cancer Registry is also located at the headquarters. By law, it is the role of the Director General for Health to run the Registry, but the responsibility has been assigned to the ICS by an agreement. Consultancy and support for patients and their significant others steadily gains importance in the work of the ICS, and this focus is reflected in increase in our financial support.

### **Income**

The Icelandic Cancer Society's income was 5.660.515 euros in 2014. Gifts accounted for 1.922.277 euros, subsidies: 3.256.286 and other income 481.951 euros.

In 2014, the Icelandic Cancer Society distributed costs on the following target areas: Research: 778.093 euros, Prevention: 3.353.419 euros, Cancer Patients Care: 502.800 euros and on other activities: 1.002.032 euros.

The financial situation of the ICS is stable, and by fiscal responsibility it has been possible to increase some aspects of the activities, e.g. information sharing. Rules on the use of funds are to be found on the webpage as is a document describing the activities and finances of the ICS.

### **Main goal**

The **main role** of the Icelandic Cancer Society is to be at the forefront of the fight against cancer. The **Goal** of the Icelandic Cancer Society is supporting and promoting in every respect the fight against cancer by for example increasing public knowledge about these diseases, supporting and conducting research, running and supporting the National Cancer Registry, screening for cancer, supporting progress in the treatment of cancer and care of cancer patients, and securing their interest in every way. **Values** of the Icelandic Cancer Society were chosen by representatives of the member associations and the employees. These are: Trust, Professionalism, Care and Respect.

### **Center for Cancer Screening**

The **screening for cervical cancer and breast cancer** is the most extensive task of the Cancer Society. From 1964 the Cancer Detection Clinic of the ICS has organized and run the screening for cervical cancer, and for mammary cancer from 1973. According to a service agreement with the Ministry of Health, the Cancer Society organizes and implements cancer screening for women from 23 to 70 years of age in case of cervical cancer and from 40 to 70 years of age in case of breast cancer. Currently, a revision of the agreement between the Icelandic Cancer Society and health authorities is underway, and hopefully the next contract will come into effect by the end of this year. The Icelandic Cancer Society has for some time advocated for population based screening for colon cancer, and emphasizes that it should start as soon as possible. In December, the insurance company OUR life (Okkar Líf) granted the ICS financial support to prepare for the organization of a public based screening for colorectal cancer. The Cancer detection clinic has undertaken changes in the organization and implementation of its screening activities. The age brackets for cervical cancer has been changed and are more in line with the other Nordic countries. Attendance was not negatively affected by the changes, which was probably also in part a result of an extensive information campaign to encourage young women to show up for screening.

### **The Icelandic Cancer Registry**

The **Cancer Registry** was established in 1954 and is among the oldest of such nationwide registries in the world. The coverage is outstanding, as information is gathered about almost every cancer diagnosed in the country. The data processing aims to accumulate knowledge about the causes and nature of cancer, and the extensive data bank allows for various types of studies, e.g. epidemiological research. Recently, registration of the stages of cancer has been included in the data collected and some clinical measures will be included, which will allow for a wider scope of research. The scientists at the Cancer Registry have published more than 500 scientific articles based on the registries data.

## Research

For the last decades the Icelandic Cancer Society has supported research in various fields of cancer, e.g. by operating a research laboratory for two decades (now moved to the University of Iceland) and collecting and preserving a valuable biobank. The ICS recently started an extensive research endeavour in collaboration with the University of Iceland, Heilsusaga (<http://heilsusaga.hi.is/>) a cohort study of 100.000 Icelanders. A new Research Fund of the Icelandic Cancer Society will be established and will support domestic research on cancer. The research fund will be built on financial support from the Cancer Society and its member cancer associations, as well as hopefully on contributions from older research funds that are currently run by the ICS.

## Patient support and information

Supporting patients and their significant others is a matter of priority by the ICS. In 2007 a new **Counselling Service** was started at the ICS, based on the work of consultants that had been in operation for decades. The Counselling Service offers information, education, psychosocial support, and various other services to those that have been diagnosed with cancer, their families and others that are affected by the diagnoses. Two nurses and a social worker are currently employed but are assisted by many other professionals. Several courses are offered for patients and others, now also for those health care professionals that work with cancer patients. Counselling via the phone (call center) is growing as individuals can call free of cost and obtain information regarding many disease related issues. The ICS co-owns eight apartments in Reykjavik where patients from the countryside can stay with significant others while being treated. Some local cancer associations have hired staff and opened **local service centers**. These are located in smaller communities in the countryside and enjoy the support of the ICS as well as the Counselling Service.

The Icelandic Cancer Society has for some years engaged itself in securing **the rights and interests** of patients, for example by putting forward information and remarks to the health authorities, commenting on relevant issues and engaging in general debates about cancer related issues. Now, the Ministry of Health is in the process of developing a new cancer plan for Iceland, and members of the cancer associations and others are hopeful that it will be useful for the cause of the cancer patients.

**Education** is instrumental in the prevention of cancer and of health promotion. The Lottery of the Icelandic Cancer Society secures finances for most of the educational activities and one of the local associations, the Cancer Society of Reykjavík, is co-responsible for that. An educational and professional advisory council has during the last few years put increasing emphasis on the website of the Cancer Society ([www.krabb.is](http://www.krabb.is)). There, general knowledge and information on various cancer issues can be found, and is updated regularly. In addition, various preventive projects are supported by the Lottery, for example actions to reduce smoking.



Patient education is one of the key roles of the ICS. A medical doctor with emphases on Public Health Science has joined the educational staff and information on the internet will be emphasized to a greater degree. A closer cooperation with the media is under way. Preventive work is often closely tied to the patient and public education, and thus cooperation between those elements is increasing.

The office of the Icelandic Cancer Society is responsible for daily management and serves the different units. The yearly turnover is about 5 million euro. Employees are now 55 in 42 fulltime positions. The main sources of income are support from the state (cancer detection clinic and registry), fees for providing services (cancer detection clinic) and support from the general public for all other aspects of the work of the ICS. Financial support from the general public and firms comes in different forms. Among these are presents, inclusive testament and commemorative presents, monthly contributions, purchases of different things sold for the benefit of the ICS, donations, and memorial cards. All are very valuable to the ICS that bases its very existence on these contributions.

### **Fundraising and public relations**

Marketing issues and campaigning have during the last year become more central in the work of the Icelandic Cancer Society. The ICS runs annually an awareness campaign and fund raising initiative in October for women under the mark of the „Pink Ribbon“. During the last seven years, March has been devoted to an action called Mustache March „Men and Cancer“.

The Department of marketing has true to form been active in fundraising and campaigning and its awareness campaigns have received acclaim in Iceland and in other countries. E.g. are the two videos that did reach viewers in many parts of the world (<https://www.youtube.com/watch?v=8jBIOoGFvBo> and <https://www.youtube.com/watch?v=8jBIOoGFvBo>).

The marketing department has also been instrumental in public relations, as the requests for the opinion of the ICS on various issues by the media keeps growing.

### **Domestic and international relations and collaboration**

**The Icelandic Cancer Society is one of the founders of Almannaheill**, union of NPOs in the third sector, and also a member of The Icelandic Association of Health Care Providers.

The member associations of the ICS change and develop constantly. Their work differs in their chosen activities, and some run service offices. At the general assembly of the ICS in the year 2014 the findings of a questionnaire regarding the satisfaction of the member associations of the collaboration with the ICS was introduced, - in short, the member associations are pleased with the umbrella organization and experience support from headquarters.

# The Norwegian Cancer Society

## *Kreftforeningen*

**Secretary General**                      **Anna Lise Ryel**  
**Chairman of the Board**                **Poul Hellandsvik**

### **Structure**

The Norwegian Cancer Society, which was founded in 1938, is a national organization addressing the challenges of cancer. We fund cancer research, support people affected by cancer as well as their families, initiate and support improvements in cancer care, engage in advocacy and place health policy issues on the agenda.

We had around 113.000 members at the end of 2014, regular financial donors, as well as thousands of individuals and associations assisting us with fundraising activities each year. The population of Norway, as a point of reference for the above, is 5 million.

The Norwegian Cancer Society is also working actively to raise the profile of cancer on the international health agenda. The Norwegian Cancer Society has three main objectives: few people should get cancer, more people should survive cancer, and ensuring the best possible quality of life for cancer patients and their families.

### **Income**

In 2014, the Norwegian Cancer Society had a total income of 63.097.453 euros. Gifts accounted for 25.790.564 euros, legacies for 12.735.436 euros, subsidies for 12.371.596 euros and others accounted for 12.199.857 euros.

Total operating costs (staff included): 62.681.232 euros.

The Norwegian Cancer Society distributed costs on the following target areas in 2014: Research: 27.351.209 euros, prevention: 1.961.505 euros, cancer patients care: 17.669.280 euros and on other activities: 6.848.201 euros.

### **National cancer strategy – words become action**

Following up on the national cancer strategy is central to the Norwegian Cancer Society's political advocacy work. Through its "Partnership against cancer", the Norwegian Cancer Society has had a hand

on the wheel of the "National action plan against cancer", which describes how the strategy turns into practical action. To ensure quick and good treatment, it is crucial that the service offered to each individual patient is well organised. It was therefore a milestone moment in 2013 when the Norwegian Cancer Society won approval for the introduction of its diagnosis-

specific cancer patient pathways initiative. In 2014, we have been involved in the design and implementation of these cancer patient pathways. User representatives have participated in almost all of the 30 working groups that have been established.

In 2014, the Norwegian Cancer Society also won approval for the creation of a contact person - a pathway coordinator - in the health authorities, who will be responsible for coordinating cancer treatment in hospital, and who the patient can turn to throughout their treatment course. The coordinator will help to ensure the patient receives the necessary information about their course of treatment and waiting times.

### **Political advocacy, public education and prevention**

Apart from the cancer patient pathways initiatives and the follow up of the national cancer strategy, the Norwegian Cancer Society has worked on service limitations for solariums and the enforcement of the age limit of 18, the HelseOmsorg 21 strategy and the extended provision of the HPV vaccine. The Norwegian Cancer Society has participated in over 30 oral and written hearings, 7 different ministries and directorates have received input for the 2016 state budget.

To ensure equal and rapid patient access to new cancer drugs, the Norwegian Cancer Society requested in a submission the preparation of a new drug report by the government examining how a national cancer drug fund could be organised and funded in Norway.

The Norwegian Cancer Society has worked systematically to persuade the authorities to introduce a licensing system for tobacco sales with a view to stopping sales to minors. With the same intention, the Norwegian Cancer Society has also advocated for ad-free packaging for tobacco products.

Statistics show that we are the world leaders in skin cancer. Therefore, Hudsjekkedagen (Skin Check Day) was an important part of the campaign to raise awareness about sun protection and the prevention of skin cancer. On 14 May 2014, Norwegian dermatologists made themselves available to check suspicious moles without the requirement for a referral from a doctor.

Various environmental factors also affect the occurrence of cancer. Some of them are related to the workplace and the carrying out of work-related duties. This applies to, among others, firefighters, who are a profession exposed to a range of carcinogenic substances. In 2014, we increased our focus on the responsibility of industry to facilitate healthier choices, and the relationship between environmental factors and cancer.

Digital media became an increasingly important channel for us to reach out to people with information. In 2014, the Norwegian Cancer Society website at kreftforeningen.no had over 1 million visitors, and the time spent on various thematic pages increased. We are also in ongoing dialogue with patients, their families and the general population on social media. The Norwegian Cancer Society's Facebook page has more than 200,000 followers.

### **Cancer coordinators in 215 municipalities**

With more people being diagnosed with cancer, more people surviving and more people living longer with the disease, there is an increasing need for municipal services. Through the investment in cancer coordinators, the Norwegian Cancer Society has worked together with the municipalities to improve local cancer care.

Funding the cancer coordinator roles remains our most important investment in cancer care. In total, the Norwegian Cancer Society has allocated EUR 24.4 million over a six year period, with EUR 4.7 million granted during 2014. This currently funds 131 roles that provide assistance to cancer sufferers and their families in 215 municipalities and districts.

The Norwegian Cancer Society hopes that the cancer coordinator service remains in place and is developed, but that the municipalities gradually take over primary responsibility for the service. In 2014, the Norwegian Cancer Society launched a financial phase-out plan that will make it easier for the municipalities to take over the service. At the same time, we also opened up to allow some more municipalities to join the scheme.

### **Varde Centres nationwide**

In 2014, the Norwegian Cancer Society and health authorities opened a Varde Centre at Stavanger University Hospital and at Haukeland University Hospital in Bergen. This means that there are now Varde Centres situated in every part of the country.

Offering a variety of services spanning from nutritional advice to legal support, the Varde Centres have consolidated their positions as important meeting places for cancer sufferers and their families. The offer of conversation with people like them from patient associations is a particularly beneficial service. A conversation with someone who has already trodden the path can help to form trust and inspiration in many people.

### **Campaigns reached new heights**

After almost 500 collections with around 20,000 collection boxes in full swing and generosity we have not seen the likes of before, the campaign to beat cancer in 2014 was a major success. In total, EUR 3.5 million was collected for research into personally adapted treatment. Rosa sløyfe (Pink ribbon) is a solidarity and enlightenment campaign run by the Norwegian Cancer Society together with the Norwegian Breast Cancer Society. Its theme in 2014 was "living with incurable breast cancer", and it was well received. The Norwegian Cancer Society's collaborative partners and supporters contributed EUR 2.7 million to the breast cancer campaign.

November has become the month of men. Once again, the Norwegian Cancer Society's message to men over 40 was as simple as it was important: Familiarise yourself with the cancer warning signs. More people than in previous years took away this critical message. 22,000 men participated in the Movember campaign, and EUR 824,000 was raised for prostate cancer research.

With the reminder that "not everyone comes home for Christmas", the Christmas campaign in 2014 was a warm success. Donations were visibly expressed in the forms of stars that were sent to hospitals, to the delight of patients and their families. Many shared their stories on social media. 5580 Christmas stars were sent to hospitals across the country. The star campaign raised EUR 309,000.

### **More volunteers and enormous commitment to the cancer cause**

Voluntary commitment is a mainstay of several of the Norwegian Cancer Society's care services, and as part of the Krafttak mot kreft campaign (All-out Effort against Cancer), voluntary efforts have become a prerequisite for success.

The number of Treffpunkt meeting places has increased, with the service now established in 29 locations around the country. This allows children and young people aged 6 to 16 years old who are related to cancer sufferers the chance to talk to each other and adult leaders. A boy aged 10 years old who had lost his mother put it like this: "At Treffpunkt I found what I had been missing - an encounter with others who were experiencing something like what I was."

The theme café was launched as a new service in 2014. People who are affected by cancer visit to have a coffee and chat - about cancer, and anything else between heaven and earth. Each theme café has a theme - sometimes related to cancer, and sometimes related to history, culture or politics. 19 theme cafés had been established before the end of the year.

### **Research during 2014**

In 2014, the Norwegian Cancer Society demonstrated how important all donations - whether they are great or small - are to cancer research in Norway. In 2014, the Norwegian Cancer Society allocated EUR 26.1 million to 133 new research projects at Norwegian universities, hospitals and other research institutions. EUR 19.8 million of this total was distributed during the main allocation period in October, with events at the Norwegian Radium Hospital and the Universities of Oslo, Bergen, Trondheim and Tromsø. At all events there was a local donor who handed over the money to the researchers. The awards in 2014 received substantial press coverage.

The 2014 King Olav V cancer research prize worth EUR 114,000 was awarded to Professor Harald Stenmark. Stenmark works on basal cell biological research. The relevance to cancer is often indirect, but his research is to a great extent concentrated on cellular processes that are relevant to cancer development. The social inequalities in health are significant and increasing in Norway. In 2014, we announced strategic research funding to examine social inequalities in health, with a long term wish to contribute to reducing social inequalities in health in terms of the occurrence of cancer and cancer mortality.

### **From research funding to seed investment**

To accelerate patient benefit of cancer research, the Norwegian Cancer Society has launched an investment initiative. The Norwegian Cancer Society wants good research to serve the patient in the form of better treatment. All too often, the development of promising products stalls due to a lack of capital. In 2014, the Norwegian Cancer Society invested EUR 458,000 in the Norwegian vaccine company Vaccibody AS, which develops a therapeutic vaccine for the treatment of severe premalignant cervical lesions.

### **The Norwegian Cancer Society and the world**

In 2014, the Norwegian Cancer Society continued its work of promoting cancer and other non-communicable diseases (cardiovascular diseases, diabetes and chronic lung conditions) on the national and international health and development agenda.

To stop the tobacco industry's inroads into Africa, the Norwegian Cancer Society is cooperating with the leading civil rights organisation for global anti-tobacco work, the Framework Convention Alliance (FCA). The Norwegian Cancer Society continued to offer its support in 2014 to a project for the early diagnosis and treatment of breast cancer in Peru in collaboration with the Norwegian Breast Cancer Society. The project is intended to increase knowledge about breast cancer among women in poor areas and put the health system in a position to take care of women suffering from cancer.

The Norwegian Cancer Society supports the work of the vaccine alliance GAVI through their global programme offering HPV vaccinations to prevent cervical cancer.

The General Secretary of the Norwegian Cancer Society was a member of Norway's delegation to the UN's high level review of non-communicable diseases in 2014, and is also a member of the WHO's Global Coordination Mechanism Working Group. The General Secretary of the Norwegian Cancer Society was re-elected as a board member of the Union for International Cancer control (UICC) for the period 2014-2016. The Norwegian Cancer Society leads the European branch of the UICC's legal network, the McCabe Centre of Law and Cancer, which shares and develops legal knowledge in the interests of the cancer cause.

### **Income**

The Norwegian Cancer Society's work is funded primarily through fund raising, bequests and support from Norsk Tipping (Norwegian National Lottery). Bequests were one of the largest sources of income in 2014 and accounted for EUR 12.7 million. We had more than 30,000 regular donors who gave us EUR 3.7 million.

We received EUR 6.9 million in response to donor letters and we received EUR 2.7 million in memorial gifts (donations given in memory of a deceased person). We received EUR 7.7 million from Norsk Tipping in 2014. The allocation of lottery funds will change significantly after 2017, and will have significant financial consequences for the Norwegian Cancer Society. In 2014, the Norwegian Cancer Society received a total of EUR 570,000 in government funding, as well as VAT compensation worth EUR 3.3 million.

### **Financial key figures**

Result for 2014: Surplus of EUR 412,000.

Use of funds for core activities:

- Research 51%
- Information/health education 10%
- Cancer care 33%
- Public relations 2%
- International work 1%
- Preventative work 4%

# The Swedish Cancer Society

## *Cancerfonden*

**Secretary General**  
**President of the Board**

**Stefan Bergh**  
**Wanja Lundby-Wedin**

### **Structure**

The Swedish Cancer Society, which was founded in 1951, is an independent, non-profit, fundraising organisation with a vision that cancer should be curable. The aim is for more people to survive and for fewer people to get cancer. The Swedish Cancer Society focuses on financing cancer research, public opinion and improving knowledge in the field of cancer. It is the single largest financer of Swedish cancer research. The Swedish Cancer Society does not receive any contributions from the government and is entirely dependent on bequests and gifts from private individuals and companies. 55 people are employed by the Swedish Cancer Society. For more information, [www.cancerfonden.se](http://www.cancerfonden.se)

### **Income**

The Swedish Cancer Society's income was 604,2 million SEK in 2014. Gifts accounted for 374,5 million SEK, legacies for 223,8 million SEK and others accounted for 5,9 million SEK.

Total operating costs (staff included) were 571,8 million SEK.

In 2014, the Swedish Cancer Society distributed costs on the following target areas:

Research: 429,9 million SEK, prevention: 49,9 million SEK and on other activities: 92 million SEK.

### **Vision, strategy and objectives**

We follow the strategic plan which includes our comprehensive, prioritized objectives that show what we want to achieve as organization until 2020. We have identified seven target areas that will get us closer to our vision which is: defeat cancer.

1. Primary prevention saves lives - 1/3 of all cancers are preventable
2. Secondary prevention saves lives - cancer should be detected earlier
3. Improved cancer care
4. Financing of the premier research
5. Human resource development
6. Efficient fundraising

## 7. Economy in balance

### **Research funding**

The aim of the Swedish Cancer Society is to support, organise and coordinate cancer research and to stimulate the development of new methods of examination, treatment and care of cancer. Researchers at universities and other higher education institutions initiate projects and present applications that are evaluated in national competition. Only the best projects are granted funding. Around seventy of Sweden's leading cancer researchers are involved in the evaluation process to select the most qualified applications for funding.

The Swedish Cancer Society evaluates research projects from all kinds of cancer research fields in competition to select the most promising projects. The projects of highest quality are funded irrespective of the area. Successful research in one area often leads to results that can be applied for other areas as well.

The Swedish Cancer Society distributed SEK 412 million in 2013 mainly to research projects, cancer research positions and travel grants. The allocation of project funding was as follows: 50 % to pre-clinical research, 32 % to translational research, 9 % clinical research, 6 % to epidemiological research; and 3 % to care research.

The Swedish Cancer Society has distributed nearly 9 billion SEK since the Swedish Cancer Society was founded in 1951. Over the same period, the number who survive cancer has more than doubled.

### **Forming public opinion**

The Swedish Cancer Society has conducted organised lobbying activities since 2006.

Pressing for improvements in this way is important to contributing to reducing incidence of cancer and increasing cancer survival.

As an independent and knowledge-intensive organisation the Swedish Cancer Society can credibly point out deficiencies, injustices, needs and future threats. It can also highlight possible solutions, international models and make concrete proposals for areas of improvement. A successful example is the work of establishing a national cancer strategy, which after many years of hard work is now under implementation.

### **Promoting knowledge development**

The organisation also possesses thorough knowledge of all cancer aspects. Highly-respected cancer researchers within the academic world have a good relationship with the Swedish Cancer Society. Leading researchers and experts in all specialities required for successful cancer research are represented on the Swedish Cancer Society's Research Commission and Prioritisation Committees. With all this intelligence capital, the Swedish Cancer Society is a natural hub in the exchange of knowledge that takes place among research, care, decision-making authorities and the general public.

For the general public and anyone interested in or concerned by cancer the website: [www.cancerfonden.se](http://www.cancerfonden.se) is an information source creating opportunities to exchange experiences and gain support using interactive tools.

### **Fundraising**



The Swedish Cancer Society raised a total of SEK 598,3 million in 2014. The Pink Ribbon campaign, breast cancer, retained its position as the strongest fundraising concept in Sweden.

Distribution of funds:

- Wills and testaments 37,41%
- Donations 54,44 %
- Lottery 5,18%
- Returns from funds 2,56 %
- Membership fees 0,05 %
- Others 0,37%

### **Finances**

The Swedish Cancer Society's operational income in 2014 was SEK 604,3 million compared to 511,4 in previous year. Total funds rose amounted to SEK 598,3 million.

Operational costs amounted to SEK 571,9 million allocated as follows:

- 429,9 million to the field of research and development
- 66,2 million for fundraising costs
- 49,9 million to distributing information and forming public opinion
- 18,4 million for Cancerfondens lottery
- 7,5 million for administrative expenses

# Contact information



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