



*The first NCU General Assembly in the Faroe Islands, Sept. 2012 – Photo: Per á Hædd*

# Annual Report 2012

## *The Nordic Cancer Union*



# Contents

- 3 NCU in short
- 4 NCU Research Grants 2012

## Member organisations

- 6 The Danish Cancer Society
  - 11 The Cancer Society of Finland
  - 13 The Faroese Cancer Society
  - 16 The Icelandic Cancer Society
  - 19 The Norwegian Cancer Society
  - 22 The Swedish Cancer Society
- 
- 25 Contact Information



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 is chaired by the Faroese Cancer Society. The chairman is Jákup N. Olsen.

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 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 NCU secretariat is located at the cancer society which holds the chairmanship of the NCU for three consecutive years. The Secretariat is responsible for general administration and coordination of NCU activities, excluding grant management which is permanently located at the Norwegian Cancer Society.

## Approved Research Grants 2012

Principal Investigator	Project Title	Project workplace (Principal Investigator)	Awarded amount (Euros)
Barkardottir, Rosa Bjork	Molecular Epidemiology of Familial Breast Cancer in the Nordic Countries: Search for Novel Genes in High-Risk Families	Head of Molecular Pathology, Landspítali University Hospital	70.000
Børresen-Dale, Anne-Lise	HER2 positive breast cancers and drug response; a Finnish-Norwegian collaboration	Dept of genetics, institute for cancer research, Oslo university hospital	70.000
Grotmol, Tom	Norwegian-Swedish genome wide association study of testicular cancer with special focus on coding regions	Cancer registry of Norway, Oslo	30.000
Hellström Lindberg, Eva	Nordic MDS Group (NMDSG) Clinical Trial program and new biobank and molecular platform to improve outcome for patients with MDS	Karolinska university Hospital	70.000
Johnsen, Hans Erik	Prognostic Classification and Prediction of Clinical Resistance in Multiple Myeloma - EMN-02 / NMSG19/10	Aalborg university hospital, Denmark	45.000
Jönsson, Göran	Molecular epidemiology of familial ocular and cutaneous malignant melanoma	Lund University	60.000
Li, Jiong	Medication during pregnancy and cancer risk in offspring: a cohort study in 2 million children in Denmark, Sweden, and Finland.	Oslo University Hospital	40.000
Lyng, Elsebeth	Mammography: from a pragmatic to an individualised screening schedule	Department of Public Health, University of Copenhagen	40.000
Mustjoki, Satu	The nordic CML study group: Immunological evaluation of factors	Helsinki University hospital	90.000

related to the successful therapy  
discontinuation

Pukkala, Eero	Work and cancer: in-depth studies initiated by the NOCCA project	Finnish Cancer Registry, Institute for Statistical and Epidemiological Cancer Research, Helsinki	70.000
Schmiegelow, Kjeld	Exploring and improving thiopurine/methotrexate maintenance therapy of acute lymphoblastic leukemia	Clinic for pediatrics and adolescent medicine, rigshospitalet, Denmark	50.000
Tammela, Teuvo	Prostate cancer screening in Finland & Sweden – Why is the efficacy so different?	Tampere University Hospital	50.000
Wiklund, Fredrik	Genetic epidemiology of prostate cancer prognosis	Dept of medical epidemiology and biostatics, Karolinska institutet, Sweden	65.000
Total			750.000

# The Danish Cancer Society

## *Kræftens Bekæmpelse*

**Managing Director**

**President of the Board**

**Leif Vestergaard Pedersen**

**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. 40.000 including participants in the annual door knocking campaign.

### **Income and Costs**

As far as concerns fundraising and income in 2012 was a successful year. The Danish Cancer Society's income was 79.904.000 euros. Gifts accounted for 53.605.000 euros, legacies for 20.023.000 euros, subsidies for 4.777.000 euros and others accounted for 1.499.000 euros.

Total operating costs (staff included) were 76.278.000 euros.

In 2012, the Danish Cancer Society distributed costs on the following target areas: Research 37.342.000 euros, prevention: 13.934.000 euros, cancer patients care: 17.553.000 euros and other activities: 7.449.000 euros.

### **Political achievements**

Act on smoke-free environments was revised in 2012. A massive pressure from the Danish Cancer Society together with other partners was put on the government. It resulted in some important improvements, hence it is now forbidden to smoke inside or outside of educational institutions area. However there is still work to be done. It is unfortunately still allowed to smoke in smoking cabins indoor.

After successfully having convinced the government that they should offer free HPV-vaccination for young girls under 27 years a campaign was launched in late summer to encourage young girls to get the vaccination to protect themselves and their best friends.

In the autumn the Danish Cancer Society's Rehabilitation Center Dallund was handed over to the Region of South Denmark to provide rehabilitation services financed by the state.

### **The Danish Cancer Society Research Center**

By the beginning of 2012 the Institute of Cancer Biology and the Institute of Cancer Epidemiology was merged into one organizational unit, i.e. the *Danish Cancer Society Research Center* (DCRC). The work of more than 160 employees from 20 nationalities is devoted cancer research with the overall purpose to add new knowledge which converts into fewer cases of cancer, better survival of patients, and improved quality of life.

The staff of DCRC is currently organized in five units: *Diet, Genes and Environment* (headed by prof. Anne Tjønneland), *Virus, Lifestyle and Genes* (prof. Susanne Krüger Kjær), *Cell Death and Metabolism* (prof. Marja Jäätelä), *Genome Integrity* (prof. Jiri Bartek), and *Survivorship* (prof. Christoffer Johansen).

The management of the new center construction consists of the Research Director and five Unit Leaders and reports directly to the Director of the Danish Cancer Society.

Some of the key results in 2012 are the importance of vitamin D in cancer causation, the role of HPV infections in men, the cancer impact of air pollution, prognostic markers for prostate cancer, individualized treatment for brain tumours, late adverse health effects after treatment for cancer in childhood, social inequality in cancer survival, and psychosocial consequences of cancer disease.

The scientific output of the Center in 2012 was summarized and presented in 292 papers published in the international peer reviewed literature. A full list of publications is available on the following link: <http://www.cancer.dk/research/publications+research+center/>

### **Quality & Patient Safety**

The Department of Quality and Patient Safety works towards improving the quality of the cancer patients' journey, with particular focus on the assessment, treatment and control processes, while also focusing on the health care system in general from a system perspective.

The Department of Quality and Patient Safety is obliged to ensure quality in the cancer process from a clinical, organizational and patient perspective with a critical eye on how outcomes are influenced by the quality of health care services and the organization of health care. Patient safety is central and a subject area of high priority. The department also collects and provides information about international developments, so that new scientific results, organizational improvements, and "best practice" from cancer care may be implemented in the Danish health care system.

Among the main results of the Department of Quality and Patient Safety in 2012 are:

- Conducted "Phase 2" of The Barometer Query focusing on the needs and experiences of 4.500 cancer patients during and after treatment (to be published in March 2013)

- Under the auspices of the *National Working Group regarding Patient Safety* presented national recommendations for improving patient safety in cancer care within the realms of chemotherapy, radiation therapy, hospital-acquired infections, pathways, post treatment, patient involvement and monitoring. The National Working Group consists of the multidisciplinary cancer groups (DMCG.dk) and the Danish Regions. The Department of Quality and Patient undertakes the groups coordinating and secretarial efforts
- Baseline measurement of the experiences of cancer patients regarding diagnostics, treatment and follow up at a single hospital (Vejle Sygehus) in order for this knowledge to guide a 5-year-program towards becoming a leading patient centered cancer hospital
- Co-hosted a Nordic research conference on patient involvement in patient safety
- Agendasetting the concept of patient centered care in the Danish health care debate (2 articles and a model of patient centered care).

Among other current projects are:

- Facilitating the development of a national plan to increase patient safety in cancer care
- Integration of PROMs (Patient Reported Outcome Measures) in a clinical cancer quality database – i.e. linking patient generated quality data with clinical and organizational data as a means to monitor patients quality of life and reactions to care and improve clinical practice
- Facilitating research on different aspects of the patient pathway (eg. from symptom to treatment, controls after end of treatment, continuity of cancer care)
- Involvement of patients in their own care and in decision making within the health care system (Patient Centered Care)
- Patient involvement at the system level of health care
- General Practitioners as supporters of cancer patients during their cancer journey (Vision Paper with PLO (main organizing body of GPs))
- Ongoing consultations with Vejle Hospital towards becoming a leading patient centered cancer hospital.

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

The Danish Cancer Society is currently building 7 modern counselling centres in the vicinity of the large oncology centres in Denmark. The counselling centres will follow a new concept combining modern architecture and counselling services with focus on empowerment of patients. The project involves a contest among young architects in Denmark, and the winners have been released for 6 centres and 3 centres will open in 2013. The new centres will be inspired by the concept of ‘healing architecture’. The centres will be placed on hospital premises, and the users can get counselling and use the facilities of the centres without appointment. The centres offer information, psychosocial support from professionals, support groups, advice on nutrition, exercise etc. The centres will collaborate with the hospital staff at the oncology centres to promote psychosocial support for cancer patients.

Patient Support and Local Activities has developed a new teaching program Ditliv (Your Life) for cancer patients and their relatives. The program focuses on positive and evidence based aspects of sleep, food, physical activity and positive thinking. In relation to the program, a large research collaboration EDITH – Evaluating Digital Therapy and Health



Interventions, will focus on developing and evaluating digital tools to promote health among cancer patients.

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 2013, a number of pilot projects involving and reaching out to new target groups will be started. Also in 2012, the focus on how to support young people with cancer has been intensified through peer support groups and a number of activities for young patients. The telephone helpline 'Kræftlinjen' will be supplemented with on line counselling and the social network Cancerforum will be improved. A large project 'Om Sorg' works to promote peer groups at schools for children, who has lost a parent.

Rehabilitation and palliative care are important issues in cancer care. In 2012, Patient Support and Local Activities released a report on cancer patients' experience of palliative care in Denmark. The report showed a number of problems related to symptoms, collaboration among care givers and involvement of relatives. Patient Support and Local Activities have a widespread local organisation all over Denmark and support the implementation of rehabilitation activities in Danish municipalities and the implementation of a report on a generic clinical pathway for rehabilitation and palliative care after cancer.

## **Cancer Prevention & Documentation**

### **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 decrease smoking and to promote smoke-free environments. From 15 August 2012 new regulations under the Smoke-free Environments Act came into force. The new regulations mean that the buildings and grounds of schools and early childhood centres are smokefree. It is no longer allowed to smoke in one-man offices. Workplaces with smoking rooms and/or smoking cabins shall put up signs informing that the air outside the smoking room/smoking cabin can be harmful.

The number of smokers is decreasing. At the end of 2012, 22 % of all adults (15+) are smokers and 17 % smoke on a daily basis.

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)), which is a complete program for the prevention of smoking start in secondary school (7th-9th form). The program is developed in connection with the initiatives of the municipalities, rules at the schools, the education, and contracts with the parents. The program is based on the good experience from Norway and Sweden.
- Our digital smoking cessation program ([www.xhale.dk](http://www.xhale.dk)) for adolescents is now also used in Norway and Sweden.

### **Prevention of cervical cancer:**

The Danish Cancer Society launched an information campaign regarding temporary free HPV-vaccine for young women aged 20-27. The campaign has successfully reached over 85 percent of the target group. Volunteers are involved in the campaign and have helped distribute information to the young women. The campaign is supported by TrygFonden and continues in 2013.

**Ethnic minority women and screening for cervical cancer and breastcancer:**

We continue our work to improve the uptake of screening by ethnic minority women. This is primarily done by focusing on peer-education i.e. by educating the communal ethnic health ambassadors to inform about the two screening programs and about the HPV-vaccine.

**Physical activity and food:**

The Danish Cancer Society has in 2012 successfully ended the project to increasing physical activity using the old fortification of Copenhagen. Through intelligent city planning there has been created new and better infrastructure for cycling and playing and supported by activity programs and apps. In 2013 the effects will be monitored and published in scientific journals. The Danish Cancer Society is developing Calorie Accounting as a health promoting tool for Supermarkets to monitor changes in calorie sales when engaging in health promoting activities. The Danish Cancer Society has achieved funding to the research project and partnered up with a Nordic supermarket chain.

**Documentation:**

NORDCAN, now updated to 2010, including regional data for all Nordic countries continues to be a success and a backbone for the ANCR-NCU collaboration. Nordic cancer incidence, mortality, prevalence, predictions and survival, as well as animated cancer maps for 33 years is now available. The thorough data collection and analysis has placed the NCU and the ANCR in the front league in Europe on use and presentation of cancer registry data in the service of the society. Danish data are now also included in the European Cancer Observatory database, EUREG, 1978-2007.

# 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 which comprises of 17 member organisations (12 regional societies and 5 national patient organisations). The CSF maintains the Finnish Cancer Registry and takes care of the administrative duties of the Finnish Cancer Foundation. It owns one laboratory and through its member organisations offer health care services. It has counselling services both nationally and regionally offering psychosocial support to patients, their near-ones, professionals and all those interested in cancer.

Number of employees: 90 at the CSF and 160 in the member organisations. Several hundred people work as volunteers for the organisation.

Main fields of activity of the Cancer Society of Finland include health promotion, counselling, cancer control, research, rehabilitation and recreation for cancer patients, palliative care, peer support, volunteers for cancer activities, cancer epidemiology and screening (quality assurance, research and planning), health service provider and communications (magazines, leaflets and internet).

### **Income**

The income of the Society was 9.899.463 euros in 2012. Gifts accounted for 11.856 euros, legacies for 1.046.956 euros, subsidies for 1.532.920 euros and others accounted for 7.307.731 euros.

Total operating costs (staff included) were 8.991.038 euros.

In 2012, the Society distributed costs on the following target areas: Research: 1.837.471 euros, prevention: 1.188.969 euros, cancer patients care: 535.543 euros and other activities i.e. health promotion, communications, Syopa-Cancer magazine: 2.126.515 euros.

### **Highlights of activities in 2012**

**New initiatives, counselling and websites**

The year 2012 started with the new leadership of the CSF. Secretary-General Sakari Karjalainen, Chief Medical Officer Liisa Pylkkänen and head of Finances and Administration Raija Stjernvall took several initiatives in developing the Society's administration and national cooperation. The basis for this development was the strategy of the Cancerorganisations 2011-2015. Counselling services with psycho-social support is one of the most important tasks of the CSF. Membership organisations play vital role in counselling. National counselling service received nearly 3 600 contacts. Of those contacts nearly 80% were made by telephone. The interactive website has been working for three years. Group chat possibility came as a new feature in 2012. A special project of counselling about familiar cancer, started in 1995, is funded by the Slot Machine Association. CSF has a main website [www.cancer](http://www.cancer) with 1,4 million visitors. The Society publishes bi-monthly magazine Syöpä-Cancer in Finnish and Swedish. The value of members was raised as a main theme for the year 2013 in national cooperation.

### **National planning**

Ministry of Social Affairs and Health set up a working group to plan a national cancer centre. The Institute of Health and Welfare set up a national expert group for preparing the second phase of the national cancer plan. It deals especially cancer prevention and early diagnosis. CSF with its stakeholders was centrally involved in both expert groups. The Finnish Cancer Registry had its 60th anniversary in 2012. Its longtime director, professor Timo Hakulinen retired at the end of the year 2012. During the fall 2012 the new director, professor Nea Malila was elected to this position. From the registry based data 72 peer reviewed articles were published and 6 dissertations were completed. The CFS with its regional and patient associations had 127 496 members at the end of the year 2012. The biggest regional organisation is the Cancer Society of Southwestern Finland with nearly 30 000 members. Cancer organisations held its annual meeting in Vaasa the Cancer Society of Ostrobothnia hosting. The theme was palliative care.

### **Health promotion, tobacco control and other activities**

In 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. The Society followed actively the tobacco products directive in the European commission and took part in the European and international collaboration (UICC, ECL and NCU). Rehabilitation, peer support and recreational courses are a part of the work of the CSF. The Society continued its 75th anniversary campaign with the theme More birthdays and 13 leading artists in Finland sang birthday songs specifically dedicated to this campaign.

# 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 2012 was 119.798 euros. Gifts accounted for 52.751 euros and others accounted for 67.046 euros.

Total operating costs (staff included) were 167.012 euros.

In 2012, the Faroese Cancer Society distributed costs on the following areas: Prevention: 1.721 euros, cancer/patients care: 11.949 euros and on other activities: 2.264 euros.

### **Activities in 2012**

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 2012 the Cancer Society has coordinated the activities in NCU and has arranged 4 NCU meetings. The general assembly and an ordinary meeting were held

in the Faroe Islands, and two meetings were held in Denmark. Coordinator of the NCU Secretariat for 2012-2014 is Birita Ludvíksdóttir, legal adviser.

### **The chairman "citizen of the year"**

In 2012 the chairman, Jákup N. Olsen, was elected "citizen of the year" for his continuing hard work to inform on and to prevent cancer in the Faroe Islands.

### **Cooperation with a sports club**

In September 2012 the Faroese Cancer Society and a local sports club entered into a partnership to provide a new sports offer for people, who have or have had cancer and their families. The offer is for free. This offer was given an award from the sports association ENGSO to be among the best innovative sports cooperations of the year.

### **"Undirlív" – HPV vaccination**

The society believes it has the greatest importance that so many young women as possible can be vaccinating against HPV-virus to protect against uterine cancer. The project "Undirlív" was launched in 2010 and continued in 2011 and 2012. Young women have received training and instruction and now organise various activities in schools, on facebook and elsewhere to encourage girls/women to become vaccinated against HPV. The name "Undirlív" is a mixture of the words uterus, wonder and life. Life is a wonderful and a healthy uterus carries a great wonder, because it creates life.

For several years the society has worked to get authorities to launch a cancer plan for the Faroe Islands. The plan was finished in October 2009 and in February 2010 was being debated by the Parliament where the plan was favourably received. In October 2011 an intersectorial working group was established to advise the Minister of Health in connection with the recommendations in the Cancer Plan. The Cancer Society is pleased that the group is established and that several of the recommendations in the Cancer Plan are already underway.

### **Activities of Help groups**

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

In April, June and November 2012 the Prostate Cancer Group had courses for men, who had or have had prostate cancer. 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.

#### **Breast cancer group "Bót til Bata"**

Self help group "Bót til Bata" wants to reach as many women, who have undergone surgery for breast cancer, as possible. In October the group arranged a meeting for women with breast 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 better provide information on how to prevent skin cancer and melanoma.

#### **Parents group**

The parents group organised a christmasparty for families of children with cancer in December 2012.

### **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 eachother.

### **Courses and education**

In September 2012 the Faroese cancer society arranged a course for healthcare professionals concerning cancer and sexlife. The purpose of the course was to highlight and disseminate knowledge about how cancer can affect a patients sex life and what healthcare professionals can do to help the problem.

### **Art therapy**

In the autumn 2012 the cancer society arranged for a course in Art therapy. The course is for people who have or have had cancer. Art therapy is about using art as a form of therapy to find the inner strength and energy in every single patient in a difficult period of life.

### **Statistics**

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 over 40 in 2012. On the other hand, the number of melanoma cancer decreased from 16 cases in 2005, to 4 - 5 cases in the past year. Far more men got prostate cancer in the last years. In 2005 there were 19 cases of prostate cancer, and in 2012 the figure was more than doubled: 40 cases were registered. 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. When it comes to abdominal cancer, the figures are very uneven. In 2008 only 7 cases were registered while in 2009 there were 29 cases registered. 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  
Sigríður Snæbjörnsdóttir**

### **Structure**

The Icelandic Cancer Society (ICS) was founded in 1951 and is a nationwide, voluntary organisation in the third sector. The Icelandic Cancer Society (ICS) consists of thirty member organizations, 8 are support groups and 22 are defined by a geographical area. The ICS Board of seven members is elected at the annual General Assembly. The main offices are in Reykjavik, but seven small service centers are in operation in the countryside. Based on a service contract with the Ministry of Welfare, the ICS runs a countrywide mammary and cervical cancer screening programs. Screening activities are centered in Reykjavik, however, health centers throughout the country participate in the actual screening, either annually or biannually. 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 is becoming a growing part of our work, and is now a specific section in our organizational chart. The Cancer League of Reykjavik is responsible for running a biannual lottery, based on an agreement with the ICS. It is stipulated in that agreement that the funds thus acquired shall be dedicated to patient information.

### **Income**

The Icelandic Cancer Society's income was 5.052.080 euros in 2012. Gifts accounted for 1.499.924 euros, memorial cards for 53.043 euros and subsidies: (state budget for screening etc.) accounted for 3.071.203 euro.

In 2012, the Icelandic Cancer Society distributed costs on the following target areas: Research: 15.554 euros, Prevention: 3.207.400 euros, Cancer Patients Care: 373.899 euros and on other activities: 1.227.841 euros.

### **Main goals**

The main role of the ICS is and has been to fight and control cancer, to improve knowledge, strengthen research, work to increase screening for cancer, support progress in treatment and care, and support patients and their significant others. In addition, we are now advocating for



a national cancer strategy, emphasizing patient advocacy and fighting for the rights of patients to a growing extent.

### **Center for Cancer Screening**

Despite the fact that a service contract till the end of 2013 between health authorities and the ICS is valid and operational, the government has decreased the funds for the activities due to the economic situation in Iceland. In 2012, we held several meetings with the Ministry of Welfare on this issue, but only succeeded to secure a part of the funds needed. We currently screen only for cervical and mammary cancer, and about 28.000 visits are recorded each year. For years now the ICS has been lobbying for a publicly based colorectal cancer screening program for Icelanders, and we are hoping to see the success of our efforts in a new national plan for health, which is under way.

### **The Icelandic Cancer Registry**

The Registry is initiating recording of the stages of the cancers recorded, and will hopefully be even more useful for clinicians and researchers based on that. It is financed in part from the state budget, but a stipend from a private company has enabled the Registry to grow and provide additional services to researchers and clinicians alike. The Cancer Registry has been active in scientific research and academic teaching, and its leaders have been actively participating in various issues regarding epidemiology of cancer and prevention.

### **Research**

Some funds for scientific research that were under the auspices of the ICS did not fare well during the crisis, and thus the Society unfortunately has limited abilities to support research. Our aim, however, is to strengthen that aspect of our work. The ICS advertised five research grants in 2011 for those involved in research on men and cancer, the funds obtained during the March campaign related to men.

Our own research activities are mainly related to the Cancer Registry, which is used extensively, and also on the use of material and data obtained through screening activities. "Heilsusaga", our ambitious research project to be conducted with the University of Iceland has not been financed as needed yet and is progressing slower than anticipated. The intent is to collect information on 100.000 Icelanders over a period of five years, by a questionnaire and biometric measurements.

### **Patient information**

This section has traditionally mainly emphasized publications and all kinds of written material but is now more involved in different methods of knowledge transfer. Increased collaboration with both the marketing section and patient support and consultancy section allows for new approaches. This collaboration has proven effective in getting a message across, and by combining fundraising and awareness campaigns we reach a larger audience. Cancer patients and their significant others can be vulnerable and many want to provide them with information, that is at times useless at best. The patient information section aims at providing relevant and evidence based information and to share it in a timely and effective manner.

### **Patient support**

The need for patient support is growing and the ICS is taking on increased responsibilities in that area. We hold conferences that are very popular in which we hear the points of view of clinicians, patients, families, civil servants and other. Lectures, courses on specific subjects

and support groups of all kinds are also a part of the program. The ICS owns 8 apartments with others, to lease for a nominal fee to patients from the countryside to use when receiving treatment in Reykjavik. This section is also the contact and support for the service centers in the countryside and for many volunteers.

### **Fundraising and public relations**

The marketing and fundraising section is very active and innovations and creativity are a part of the game. The result is that many are inspired and participate in our work, e.g. by creating things to sell or making interesting contributions.

The Pink October and the Men and March (Moustache March) continue to be our main awareness and fundraising activities. Monthly contributors are getting more numerous, and we value their support greatly.

### **Advocacy and patient rights**

The ICS has been active in advocating for patients, trying to ensure that the out of pocket payments are reasonable. The cost of being diagnosed with cancer keeps growing, and we point this out to the authorities at every chance we get. Due to the economic situation in Iceland, funding for health care services are cut, and we watch that trend closely and speak out on severe occasions.

We are urging the Alþingi to revise the legislation on patient rights, and want to take part in that revision.

The government put a new bill of law on the cost of medications on the table, which would increase out of pocket payment for cancer patients considerably. Our comments on the bill will hopefully influence the legislation, as the cost of health care is becoming too high for many.

### **Grass root activities**

The activities of the member organizations are as varied as they are many. They are very independent, and focus on issues that are of relevance to them. The structure for support of these activities has been revised, and a closer cooperation is expected as a result.

# 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. Our primary sources of income in 2012 were collected donations, bequests and gaming pool funds from Norsk Tipping.

We had 111.330 members at the end of 2012, regular financial donors, about 350 volunteers engaged in activities involving cancer patients and their families, 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.

### **Income**

In 2012, the Norwegian Cancer Society had a total income of 65.100.000 euros. Gifts accounted for 20.200.000 euros, legacies for 19.400.000 euros, subsidies for 13.800.000 euros, financial income for 9.800.000 euros and others accounted for 1.900.000 euros.

The Norwegian Cancer Society distributed costs on the following target areas in 2012: Research: 24.000.000 euros, prevention: 1.800.000 euros, cancer patients care: 18.000.000 euros and on other activities: 18.200.000 euros.

### **Our main goals**

- Contribute with preventative efforts so that more people can avoid getting cancer.
- Contribute to more people surviving cancer.
- Ensure the best possible quality of life for cancer patients and their loved ones.

### **Research in 2012**

The Cancer Society granted about 24 million Euros to cancer research in 2012. This means that the Norwegian Cancer Society funds approximately 25 percent of cancer research in Norway and about 200 research projects in all types of cancer.

Research supported by the Cancer Society is assessed according to quality before funds are awarded. The primary focus is on investigator-initiated projects with grants being allocated on a competitive basis. Applications for research grants are evaluated by peer review groups before the research committee makes its final proposal to the Board.

The Cancer Society's investments in cancer research are essential in ensuring that Norwegian patients benefit from international cooperation and exchange of knowledge. Increasing the total resources available to cancer research and having the government assume greater responsibility for cancer research are among our priorities.

King Olav V's Cancer Research Prize of NOK 1,000,000 (About 13.000 Euros) was established by the Cancer Society and is a prestigious annual event. In 2012, HM King Harald V presented the prize to Claes Tropé, professor at Oslo University Hospital. Trope has been in the front of introducing new treatments for gynecological cancer. This has improved survival and led to reduced injuries and side effects in women receiving treatment. It applies primarily to cancer of the cervix, uterus and ovaries.

In 2012, the theme for our annual campaign 'Krafftak mot kreft' (All-out Effort against Cancer) was "Research on cancer diseases few people survive". Extensive cancer research over many years has resulted in 2 of 3 people with cancer survive. However, there are large differences in survival, depending on the cancer form. While some cancers have survival rates around 90%, others are in the opposite end of the scale. For example: lung-, esophagus- and pancreas cancer. The three cancers taking nearly 3,000 lives in Norway - every year. The overarching goal of the campaign was to generate more research on cancer diseases with low chance of survival. Money for the fund was collected through collection-boxes and the Sounds of Winter concert tour.

The Cancer Society also had an annual campaign for 'Rosa Sløyfe' (Pink ribbon). The theme for 2012 was personalized treatment. Rosa Sløyfe was held in October, and the profits of the operation were NOK 13.9 million.

### **Volunteers in 2012**

Volunteers are an increasingly important and visible part of care provision in the Cancer Society. In 2012 there were approximately 350 volunteers active at the Cancer Society offices, Vard centers or hospitals. 45 of the volunteers are legal experts. In 2012 over 17,000 volunteers participated in the Cancer Society raising campaigns.

### **International work**

Globally, cancer is causing 8 million deaths annually and more than 70 percent of deaths occur in low and middle income countries. Cancer takes more lives than HIV / AIDS, malaria and tuberculosis combined. In 2012, the Cancer Society has been actively working to raise focus on cancer and non-communicable diseases at the national and international health and development agenda.

### **Patient associations**

Twelve independent associations representing people affected by cancer and their families are associated members of the Cancer Society. The associations offer peer support, training and activities and have a combined membership of 30,000. The Cancer Society allocates about 2, 7 million Euros to the associations' work each year.

### **Information work**

Our website ([www.kreftforeningen.no](http://www.kreftforeningen.no)) was used frequently more by the public than any previous year (over 800,000 hits). We are also very active on social media such as Facebook, Twitter and YouTube. More than 400,000 followed the different sites we had on Facebook in 2012, and we blog regularly. We produce brochures and fact sheets for patients and their families, informational materials for members and a magazine called 'Sammen mot kreft' (Together against Cancer). We have a leading position in the news through articles and editorials.

### **Advocacy and public relations**

The Cancer Society has worked for several years for a new cancer strategy plan. In 2012 the Cancer Society got a breakthrough by the Minister of Health started working on a new cancer strategy. The Cancer Society collaborates with the Health Directorate about the preparation of a new strategy and the proposal will be submitted to the Ministry of Health in March 2013.

The Cancer Society worked on several cases in 2012. For example, the Government proposed changes in the tobacco law, where the Cancer Society practically got approved all their suggestions and the Cancer Society also worked hard to strengthen the patients' rights in relation to waiting times for treatment of cancer.

The Cancer Society staff is represented in approximately 130 boards, councils, committees and working groups at a national and a regional level and has participated in several international delegations.

### **Financial key figures**

Result for 2012: NOK 10,8 million in plus.

- Areas of focus:
- Research 47%
  - International Activities 1%
  - Care for cancer patients 35%
  - Public Affairs 2%
  - Information 12%
  - Preventive 3%

# 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. 52 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 61.3 million euros in 2012. Gifts accounted for 27.9 million euros, legacies for 26.5 million euros and others accounted for 6.9 million euros.

Total operating costs (staff included) were 65.3 million euros.

In 2012, the Swedish Cancer Society distributed costs on the following target areas: Research: 48.4 million euros, prevention: 4.8 million euros and on other activities: 12.1 million euros.

### **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 2015. 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 goal of the Swedish Cancer Society is to support, organise and coordinate cancer research and stimulate 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 assessed in competition on a national level. Only the best projects are granted funding. Around seventy of Sweden's leading cancer researchers are involved in ranking the research funding applications in order of priority.

The basic principle for the Swedish Cancer Society is to allow all research projects to compete with each other regardless of the type of cancer they refer to. Successful research in one area often leads to results that can be used in other areas as well.

The Swedish Cancer Society distributed SEK 404 million in 2012 to research projects, cancer research positions, grants and other areas. The allocation of project funding was as follows: 53 % to Pre-clinical Research, (significant research of the basic mechanisms of cancer and thus lending a strong bearing on all on all clinical research specialisations); 15 % to Clinical Research, (patient research); 7 % to Epidemiological Research; 21 % to Translational Research and 4 % to Care Research.

We have distributed nearly 9 billion since the Swedish Cancer Society was founded in 1951. Over the same period, the number who survive cancer has 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 credibility 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 504 million in 2012. The Pink Ribbon campaign, breast cancer, retained its position as the strongest fundraising concept in Sweden.

Distribution of funds:

- Wills and testaments 43 %
- Donations 45 %
- Lottery 7 %
- Returns from funds 3 %
- Membership fees 1 %
- Others 1%

## **Finances**

The Swedish Cancer Society's operational income in 2012 was SEK 511 million compared to 450 in previous year. Total funds rose amounted to SEK 504 million.

Operational costs amounted to SEK 545 million allocated as follows:

- 404 million to the field of research and development
- 69 million for fundraising costs
- 40 million to distributing information and forming public opinion
- 22 million for Cancerfondens lottery
- 11 million for administrative expenses



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