



The Secretary Generals of the NCU – Photo: Per á Hædd

Annual Report 2011

The Nordic Cancer Union



Contents

- 3 NCU in short
- 4 NCU Research Grants 2011

Member organisations

- 5 The Danish Cancer Society
- 9 The Cancer Society of Finland
- 11 The Faroese Cancer Society
- 15 The Icelandic Cancer Society
- 18 The Norwegian Cancer Society
- 21 The Swedish Cancer Society

- 24 Contact Information



Nordic Cancer Union
www.ncu.nu

NCU Secretariat

c/o The Faroese Cancer Society (Krabbameinsfelagið), att. Birita Ludvíksdóttir, coordinator,
P.O. Box 1216, FO-110 Tórshavn, the Faroe Islands, tel.+298 31 79 59, mob.+ 298 21 79 56,
e-mail: ffk@krabbamein.fo and birita@krabbamein.fo

NCU Research Administration

c/o Norwegian Cancer Society (Kreftforeningen) I Postboks 4 Sentrum 0101 Oslo, Norway
Phone: +47 815 70 477 I e-mail: ncu@kreftforeningen.no

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 directed by a Board consisting of chairmen and Secretary Generals of the NCU member organisations. While the Board meets annually the Secretary Generals of the Nordic cancer societies meet 3-4 times a year to coordinate joint activities and to prepare recommendations for the Board.

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 2011

| Principal Investigator | Project Title | Project workplace (Principal Investigator) | Amount (€) |
|--------------------------|---|--|----------------|
| Barkardottir, Rosa Bjork | Molekular Epidemiology of Familial Breast Cancer in the Nordic Countries: Using Next Generation Sequencing in the Search for Novel Genes in Hight-Risk Breast Cancer Famililies | Head of Molecular Pathalogy, Landspítali University Hospital | 60 000 |
| Børresen-Dale, Anne-Lise | Her2+ breast cancers and drug reponse; a Finnish-Norwegian collaboration | Oslo University Hospital - Radiumhospitalet | 90 000 |
| Bretthauer, Michael | NordICC – The Nordic-European Initiative on Colorectal Cancer | Oslo University Hospital, Oslo, Norway | 75 000 |
| Brown, Peter de Nully | The Nordic Lymphoma Group: a bench-to-bedside approach to improve management and outcome of patients with malignant lymphoproliferative diseases in the Nordic countries | Dept. Haematol 4042, Rigshospitalet, | 40 000 |
| Høyer, Morten | Non-Surgical treatment of colorectal liver metastases | Department of Oncology, Aarhus University Hospital | 50 000 |
| Kaprio, Jaakko | Genetic and Environmental Contributions to Cancer - The NorTwinCan study of cancer in Nordic Twins | University of Helsinki, Department of Public Health | 85 000 |
| Lynge, Elsebeth | Mammography: From a pragmatic to an individualised screening schedule | Department of Public Health, University of Copenhagen | 70 000 |
| Oldenburg, Jan | Prevention of germ cell cancer in Scandinavian males with testicular dysgenesis syndrome | Oslo University Hospital-Ullevål Kreftseneter | 85 000 |
| Pukkala, Eero | Work and cancer: in-depth studies initiated by the NOCCA project | Finnish Cancer Registry, Institute for Statistical and Epidemiological Cancer Research, Helsinki | 85 000 |
| Rosenquist, Richard | Comprehensive Molecular Screening and Large-Scale Data Integration in a Population-Based Cohort of Chronic Lymphocytic Leukemia | Dept of Immunology, Genetics and Pathology, Uppsala University | 50 000 |
| Wiklund, Fredrik | Genetic epidemiology of prostate cancer prognosis | Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Stockholm | 60 000 |
| Total | | | 750 000 |

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 455.000 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.

646 people are employed by the Danish Cancer Society within research, patient support and prevention/information. The number of volunteers are app. 39.000 including participants in the annual door knocking campaign.

Income and Costs

As far as concerns fundraising and income in 2011 was a successful year. The Danish Cancer Society's income was 66.013.000 euros. Gifts accounted for 40.154.000 euros, legacies for 20.280.000 euros, subsidies for 3.886.000 euros and others accounted for 1.693.000 euros.

Total operating costs (staff included) were 70.036.000 euros.

In 2011, the Danish Cancer Society distributed costs on the following target areas: Research 32.347.000 euros, prevention: 12.704.000 euros, cancer patients care: 17.246.000 euros and other activities: 7.738.000 euros.

Political achievements

The Danish Cancer Society succeeded in 2011 in persuading the Danish Government that the national HPV-vaccination programme for girls aged 12 could not stand alone. The society strongly advocated for free vaccination of all women up to age 27. The result was a catch up programme to vaccinate young women aged 20- 27. The catch up programme will start in august 2012. The Danish Cancer Society has decided to launch a major campaign to reach the ambition of the highest rate of HPV-vaccination in the world.

In 2011, the Danish Cancer Society worked to influence the law on passive smoking to be more restrictive. The Danish cancer Society wanted among other things strict rules for schools with children under 18 and a total ban on smoking indoor. Together with other health

organizations the society managed to gain a total ban on smoking in schools during school hours and succeeded in getting a ban on smoking indoor, however there are still some exceptions, for example it is allowed to smoke in cabins indoor and smoke in small pubs. Furthermore higher taxes as well as pictorial warnings on cigarette packs were decided in Parliament.

The Danish Cancer Society Research Center

To fuel research synergy and to maintain competitive power at highest international level the Danish Cancer Society decided in 2011 to merge its two research institutes, the Institute of Cancer Biology and the Institute of Cancer Epidemiology, into a cross-disciplinary entity under a unified leadership. The name of the new entity, which assembles 180 scientists and technicians, is simply *The Danish Cancer Society Research Center (DCRC)*. The DCRC is a major cancer research player in Denmark, acknowledged for its world-class research – with a strong focus on public health, and the life of the cancer patient. The overall goals for DCRC are:

- to combine complementary cancer research disciplines while maintaining scientific strongholds
- to feed a challenging and ‘seamless’ environment for the next generation of talented researchers
- to communicate research results to the national and international community, not least to patients,
- relatives and supporters of the Danish Cancer Society.

The staff of DCRC is currently organized into six 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), *Survivorship* (prof. Christoffer Johansen) and *Translational Oncology* (under recruitment). The management of the new center construction consists of the Research Director and six Unit Leaders and reports directly to the Managing Director of the Danish Cancer Society. The scientific output of the Center is summarized in 240 papers published in the international peer reviewed literature for 2011. A full list of publications is available using this link: (<http://www.cancer.dk/forskning/center+for+kraeffforskning/publikationer+center+kraeffforskning/>).

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 2011 are:

- Publishing the results of a large scale survey of Danish cancer patients (The

Barometer Query) aimed at pinpointing areas for improvement of cancer care from first symptom to the end of treatment. Link to article in Danish:

http://www.cancer.dk/fagfolk/noegletal_og_baggrundsviden/patienten+sunhedsvaese+n+barometerundersoegelsen/Barometerundersoegelsen/barometerundersoegelsen.htm

- Launching Phase 2 of The Barometer Query focusing on the needs and experiences of cancer patients during and after treatment
- The reporting of harmful incidents from cancer patients to the patient insurance service
- Handbook and a toolkit supporting clinical staff and leadership efforts towards improving quality of services. Link to handbook in Danish:
<http://www.cancer.dk/fagfolk/behandling/haandbog+kvalitetsforbedring/>

Among other current projects are:

- Facilitating the development of a national plan to increase patient safety in cancer care
- Integration of PROMs (Patient Recorded 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
- Consultation with Vejle Hospitals aspirations towards becoming a leading patient centered cancer hospital.

Patient Support & Community Activities

Patient Support close to the oncology centres and in the communities

The Danish Cancer Society is currently building 7 modern counselling centres in the vicinity of the large oncology centres in Denmark. The centres will follow a new concept combining modern architecture and counselling services with focus on empowerment of patients. The centres are partly financed by donations from the Realdania Foundation and 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 and relaxation therapies etc.

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. Patients and relatives together are offered a 4 day teaching program and a website with tools and information materials has been developed to support life changes in the four focus areas of Ditliv.

In 2011 Patient Support and Local Activities started a process to develop a new strategy for patient support, involving employees, key users and external experts in the process. The new strategy will focus on empowerment of users and how to reach new target groups such as men, ethnic minorities and socially vulnerable users.

Cancer rehabilitation is an important issue in survivorship support in Denmark. Patient Support and Local Activities has participated in a national initiative from the national Board of Health to publicise a generic clinical pathway for rehabilitation and palliative care after cancer. The pathway defines the tasks of hospitals, municipalities and family doctors in rehabilitation. The Cancer Society has local committees in nearly all municipalities and will follow the implementation of the rehabilitation pathway closely and offer patients support in the local communities.

Cancer Prevention & Documentation

Tobacco: Continued debate and political pressure are finally evident in the sales figures for cigarettes. From 2010 to 2011 sales dropped with 10 %. Also the number of smokers is decreasing. At the end of 2011, 24 % of all adults (15+) are smokers and 18 % smoke on a daily basis. A revised internet based cessation program was launched in 2011.

Diet and physical activity: The Danish Cancer Society has successfully continued the project increasing physical activity using the old fortification of Copenhagen for cycling, playgrounds, supported by activity programs and apps. 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 applied for funding to the research project and partnered up with a Nordic supermarket chain.

Breast cancer screening: The national screening program for breast cancer is now showing an increase as expected in the incidence of breast cancer.

Sun safety: The sun safety campaign, run by The Danish Cancer Society and TrygFonden, continues to be successful in increasing awareness of sun safety, changing attitudes to sun protection and reducing sunbed use. The Danish team is *helping NCU* developing a set of ethical guidelines on UV safety for the Scandinavian Travel Industry. Volunteers are involved in campaigns and supplied over 6,000 hours of their time in 2011. Pre-testing, evaluation and monitoring of all activities remain an integrated part of daily campaign work.

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.

The Cancer Society of Finland

Cancerforeningen i Finland

**Secretary General
Chairman**

**Dr. Sakari Karjalainen
Professor Teuvo Tammela**

Structure

The Cancer Society of Finland, founded in 1936, is one of Finland's largest public health organisations. It is an umbrella organisation for 17 registered member organisations (12 regional societies and 5 national patient associations). The society maintains the Finnish Cancer Registry and takes care of the administrative duties of the Finnish Cancer Foundation. It owns a laboratory and through its member organisations and foundations it owns three hospices and offers health care services and rehabilitation. It has counselling services both nationally and regionally.

66 people are employed by the organisation and 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 11.341.800 euros in 2011. Gifts accounted for 219.700 euros, legacies for 1.274.300 euros, subsidies for 1.335.000 euros and others accounted for 8.512.800 euros.

Total operating costs (staff included) were 11.282.000 euros.

In 2011, the Society distributed costs on the following target areas: Research: 1.710.100 euros, prevention: 1.032.200 euros, cancer patients care: 525.800 euros and other activities i.e. health promotion, communications, Syopa-Cancer magazine: 2.446.300 euros.

Highlights of activities in 2011

The Cancer Society of Finland celebrated its 75th anniversary in 2011 with number of events and publications under the theme "More Birthdays".

The Society organised seminars for health care professionals across the country to introduce them with the idea of the Cancer Strategy in 2020. These seminars underlined the importance of the Society as a national focal point for cancer information. These seminars got very positive feedback from the audience.

The anniversary year ended under new leadership. Secretary General Harri Vertio retired and Dr Sakari Karjalainen, Director General at the Ministry of Education and Culture, was nominated as the fourth Secretary General of the Society. He took office 1st of December 2011.

Dr Liisa Pylkkänen, MD Ph.D. was nominated as the new chief Medical Officer of the Cancer Society. Pylkkänen was earlier Head of Department at the European Organisation for Research and Treatment of Cancer (EORTC) in Brussels.

The third nomination was the Head of Finance and Administration. Raija Stjernvall succeeded Eero Keränen in this position in January 2012.

The statutory registration of cancers continued as before. During the year, there were 80 scientific studies published that relied on the data of the Finnish Cancer Registry. Three of them were doctoral dissertations.

An article on the scope and results of the first and second rounds of screening for colorectal cancer was published in summer 2011.

The Cancer Foundation granted 4.4 million euros to research in 2011.

Breast cancer in the family was the theme of the Pink Ribbon campaign. The campaign made its best result ever and raised more than 670. 000 euros for breast cancer research and counselling.

The regional cancer societies organised cancer rehabilitation courses. More than 3 000 cancer patients and their family members participated in these courses. The funding came mainly from Finland's Slot Machine Association and Kela (the Social Insurance Institution of Finland).

Web counselling service neuvontahoitaja.fi was in its second year. A group chat service was introduced to the site.

Cancer Society started cooperation with the Clinic of Oncology in Helsinki Uusimaa Hospital District (HUS) and set up a counselling service at the clinic staffed by a nurse from the Cancer Organisations.

Various activities throughout the year

“Undirlív” – HPV vaccination

The society believes it has the greatest importance that so many young women as possible can be vaccinated against HPV-virus to protect against uterine cancer. The project “Undirlív” was launched in 2010 and continued in 2011. 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.

Supporting research

The Cancer Society donated DKK 230.000 for breast cancer research. This is a project that doctors at our National Hospital have begun. Faroe Islands are also part of a research project on social costs of cancer, with which Nordic Cancer Union (NCU) is working.

Cancer Plan

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

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 where 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.

Parents group

The parents group organised a successful trip for families with children, who have or have had cancer.

Art therapy

Art therapy is a new offer that the Cancer Society offers cancer patients. The offer 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.

Look good feel better

Again this year the Cancer Society held courses in skin and facial care for women, who receive cancer treatment.

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. Yet another very active year has passed. In October the group focused on breast cancer by organising an evening for women who have or have had breast

cancer. There were fashion shows, lectures, music and fun. Also, the group sold necklaces for the benefit of breast cancer.

The prostate cancer group

The prostate cancer group organised a lecture with the urologist, Johan Poulsen. The lecture was based on questions that the group had gathered since the group started its activities in September 2010.

The uterus group

The uterus group arranged cozy evenings for the group. The aim is that women talk to women in the same situation as themselves and in this way help themselves. The group organised an evening together with the breast cancer group in February where they talked about common problems and difficulties.

The Melanoma group

The group met regularly for conversation 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.

Educating helpers and staff

App. 40 helpers are connected to the Cancer Society. These helpers are doing a very important job for the Society. In September, Inge Kaldahl Friberg, director of cancer advice in the Danish Cancer Society, visited the Cancer Society. She is educated psychologist and nurse. She taught and lectured staff and helpers of the Faroese Cancer Society.

Welcome support gives strength

As always, there are many who support the Society in various ways. Donations allow the Society to maintain a high level of activity. 2011 was no exception. Pupils from a village school in the Faroe Islands had a concert in favour of cancer and donated app. DKK 33.000 to the Cancer Society. In April, a Faroese artist, had an exhibition that put light on cancer. A portion of the profits, DKK 11.000, was donated to the Cancer Society. The "Movember Movement" has also come to the Faroe Islands. In November, a director of a Faroese company, gathered 161 men with beautiful mustaches to be photographed for a book. The profits of the sale of the book were donated to the Faroese Cancer Society. Unfortunately, we cannot mention everyone who has supported us, but the Society takes this opportunity to say thank you for all the great support.

Cancer Registration and NORDCAN

The Faroe Islands have updated the registration of cancer cases up to 2011. It is now possible to see the Faroese numbers on the internet and compare them with those from other countries. Below there is a list of cancer cases in the Faroe Islands for the last 7 years.

Altogether

| 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 |
|-------------|-------------|-------------|-------------|-------------|-------------|-------------|
| | | | | | | |
| 230 | 207 | 229 | 219 | 237 | 235 | 205 |

Lungcancer

| 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 |
|------|------|------|------|------|------|------|
| | | | | | | |
| 14 | 7 | 14 | 17 | 14 | 15 | 15 |

Breastcancer

| 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 |
|------|------|------|------|------|------|------|
| | | | | | | |
| 20 | 20 | 26 | 26 | 24 | 24 | 22 |

Prostatecancer

| 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 |
|------|------|------|------|------|------|------|
| | | | | | | |
| 19 | 26 | 28 | 28 | 45 | 38 | 44 |

Melonoma

| 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 |
|------|------|------|------|------|------|------|
| | | | | | | |
| 16 | 12 | 6 | 7 | 4 | 7 | 6 |

Skincancer

| 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 |
|------|------|------|------|------|------|------|
| | | | | | | |
| 39 | 45 | 41 | 35 | 44 | 45 | 22 |

The Icelandic Cancer Society

Krabbameinsfélag Íslands

**Director
Chairperson**

**Ragnheiður Haraldsdóttir
Sigriður 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 consists of thirty organisations, 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. The number of employees in the Icelandic Cancer Society is 50 people. Based on a service contract with the Ministry of Welfare, the ICS runs mammary and cervical cancer screening program in the country. Screening activities are centered in Reykjavik, however, health centers throughout the country participate in the actual screening, either annually or biennially. 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 organisational 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 4.663.290 euros in 2011. Gifts accounted for 1.299.359 euros, memorial cards for 83.670 euros, legacies for 216.650 euros and subsidies: (state budget for screening etc.) accounted for 2.765.576 euro.

In 2011, the Icelandic Cancer Society distributed costs on the following target areas: Research: 15.488 euros, Prevention: 3.189.115 euros, Cancer Patients Care: 338.098 euros and on other activities: 994.299 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 2011, the Societies laws were adjusted to the fact that we are now advocating for a national cancer strategy, and 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. Thus, the program is currently run with a deficit. We screen for cervical and mammary cancer, and about 28.000 visits are recorded each year. The ICS General Assembly in 2011 decided that screening for colorectal cancer should be the next screening priority and we are pushing for preparation for the next steps in that regard.

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.

Research

Some funds for scientific research that were under the auspices of the ICS did not fare well during the crisis, and are currently not supporting research. 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. In December, the University of Iceland and the Icelandic Cancer Society signed a framework contract for an ambitious cohort research proposal that will be implemented in cooperation with Harvard School of Public Health-(Heilsusaga). 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 of the services of the ICS 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 can at times be 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 country side 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 continue to be our main awareness and fundraising activities. In March, we get visits to our home page from 120.000 different computers and from 124 countries. 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 for health care 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 Minister of Health stated in February 2011 that Icelanders will get their Cancer Plan, something we had been hoping for-and he announced that this was linked to the 60 years anniversary of the ICS. Progress, however, is slow.

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 organisation 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 are collected donations, bequests and gaming pool funds from Norsk Tipping.

We have around 180 employees, more than 110.000 members and regular financial donors, more than 200 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 2011, the Norwegian Cancer Society had a total income of 47.600.000 euros. Gifts accounted for 18.000.000 euros, legacies for 16.000.000 euros, subsidies for 12.000.000 euros and others accounted for 1.600.000 euros.

The Norwegian Cancer Society distributed costs on the following target areas in 2011: Research: 25.000.000 euros, prevention: 2.000.000 euros, cancer patients care: 15.000.000 euros and on other activities: 19.300.000 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 2011

Cancer Society granted about 25 million Euros to cancer research in 2011. The Norwegian Cancer Society has never granted as much as in 2011! This means that the Norwegian Cancer Society funds approximately 25 percent of cancer research in Norway.

Research supported by the Norwegian 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 Norwegian 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 750,000 (About 10.000 Euros) was established by the Norwegian Cancer Society and is a prestigious annual event. In June 2011, HM King Harald V presented the prize to Sverre Heim, professor at the Department of Medical Informatics at Oslo University. Heim is studying chromosomal aberrations in cancer. In most cancer diseases, there are found chromosomal abnormalities that affect the development of the disease and which may also have implications for how the disease should be treated. Heim has become a world leader in the field.

In 2011, 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.

Volunteers in 2011

Volunteers are an increasingly important and visible part of care provision in the Norwegian Cancer Society. In 2011 there were approximately 220 volunteers active at the Cancer Society offices, Vard centers or hospitals. In 2011, the Norwegian Cancer Society started a project to bring in lawyers that volunteered to advise patients and relatives.

International work

In 2011, The Norwegian Cancer Society was active in putting cancer and so-called "non-contagious diseases" (NCD) on the national and global health agenda. Also, in 2011, the Norwegian Cancer Society's international cancer prevention work was carried out through our engagement in tobacco prevention projects in Africa and northwest Russia. We received funding from the Ministry of Health and Care's Barents Programme to test and adapt the Norwegian tobacco prevention programme 'Free' to schools in Arkhangelsk.

Patient associations

Twelve independent associations representing people affected by cancer and their families are associated members of the Norwegian Cancer Society. The associations offer peer support, training and activities and have a combined membership of 30,000. The Norwegian Cancer Society allocates about 27 million Euros to the associations' work each year.

Information work

The Norwegian Cancer Society disseminates information through an array of channels. Our website www.kreftforeningen.no was used frequently more by the public than any previous year. (Approximately 650.000 hits). The Norwegian cancer society is also very active on

social media such as Facebook, Twitter and YouTube. More than 350,000 followed the different sites we had on Facebook in 2011, 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

In 2011, we have specially focused on, and received approval for publication of waiting times and a shorter waiting time in cancer treatment. We also received approval for our proposal for designated care takers at the hospitals for all cancer patients. We have also actively worked to reduce waiting time for reconstruction of the breast, which so far has resulted that the health minister has said that reconstruction should be included in course of treatment for breast cancer.

Financial key figures

Result for 2011: NOK 104 million in minus. Income: NOK 347 million.

Areas of focus: - Research 52%
- International Activities 1%
- Care for cancer patients 29%
- Public Affairs 2%
- Information 12%
- Preventive 4%

The Swedish Cancer Society

Cancerfonden

Secretary General **Stefan Bergh**
President of the Board **Bengt Holgersson**

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. 49 people are employed by the Swedish Cancer Society. For more information, www.cancerfonden.se

Organisation

In September 2011 Stefan Bergh entered as General Secretary of the Swedish Cancer Society. He succeeded Ursula Tengelin. A new office organization was executed on the 1st of December, 2011. A new department, Public Affairs, was created in the new organization. The department's task is to strengthen the organization's position in the political sphere of work with emphasis on advocacy and dissemination of knowledge.

Income

The Swedish Cancer Society's income was 49.8 million euros in 2011. Gifts accounted for 23.3 million euros, legacies for 22.0 million euros and others accounted for 4.6 million euros.

Total operating costs (staff included) were 59.7 million euros.

In 2011, the Swedish Cancer Society distributed costs on the following target areas: Research: 43.6 million euros, prevention: 4.5 million euros and on other activities: 11.6 million euros.

Vision, strategy and objectives

A strategic plan for the organization was formed in the autumn of 2011. The plan 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

During 2011 the Swedish Cancer Society made extensive work on the trademark of Cancerfonden that resulted in a new brand platform. Out of this work a new vision was made: defeat cancer. Another important aspect was to identify and strengthen our values: Knowledge, Commitment, Perseverance and Innovation.

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 394 million in 2011 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.

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 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 443 million in 2011. The Pink Ribbon campaign, breast cancer, retained its position as the strongest fundraising concept in Sweden.

Distribution of funds:

- Wills and testaments 44 %
- Donations 43 %
- Lottery 8 %
- Returns from funds 4 %
- Membership fees 1 %

Finances

The Swedish Cancer Society's operational income in 2011 was SEK 450 million compared to 440 in previous year. Total funds rose amounted to SEK 443 million.

Operational costs amounted to SEK 539 million allocated as follows:

- 394 million to the field of research and development
- 72 million for fundraising costs
- 40 million to distributing information and forming public opinion
- 21 million for Cancerfondens lottery
- 12 million for administrative expenses

Contact information



Kræftens Bekæmpelse

The Danish Cancer Society

Strandboulevarden 49, DK-2100 Copenhagen
Ø, Denmark

Managing Director: Leif Vestergaard Pedersen

Phone: +45 35 25 75 00

Email: info@cancer.dk

www.cancer.dk

krabbameinsfelagið



The Faroese Cancer Society

Grønlandsvegur 58, Boks 1216, FO-110
Tórshavn

Director: Jansy Gaardlykke

Phone: +298 31 79 59

Email: ffk@krabbamein.fo;

www.krabbamein.fo



Cancer Society of Finland

The Cancer Society of Finland

Pieni Roobertinkatu 9, FI-00130 Helsinki,
Finland

Secretary General: Sakari Karjalainen, MD,
PH.D.

Phone: +358 9 135 331

Email: society@cancer.fi

www.cancer.fi



Krabbameinsfélagið

The Icelandic Cancer Society

Skógarhlíð 8, IS-105 Reykjavik, Iceland

Director: Ragnheiður Haraldsdóttir

Phone: +354 540 1900

Email: krabb@krabb.is

www.krabb.is



The Norwegian Cancer Society

Visiting address: Tullins gate 2,

Postal address: PO Box 4 Sentrum, 0101 Oslo,

Secretary General: Anne Lise Ryel

Phone +47 815 70 477

E-mail: servicetorget@kreftforeningen.no

www.kreftforeningen.no

Cancerfonden

The Swedish Cancer Society

Visiting address: David Bagares gata 5,

Postal address: 101 55 Stockholm

Secretary General: Stefan Bergh

Phone: +46 8 677 10 10

Email: info@cancerfonden.se

www.cancerfonden.se



Ålands Cancerförening

OBSERVER STATUS:

The Cancer Society of Åland

Nyfahlers, Skarpansvägen 30, AX-22100

Mariehamn

Director: Helka Andersson

Phone: +358 18 22 419

Email: info@cancer.ax

www.cancer.aland.fi