



*Godafoss, Iceland*

# Annual Report 2016

## *The Nordic Cancer Union*





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

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# NCU

## *in short*



*Ragnheiður Haraldsdóttir,  
NCU chairman*

The Nordic Cancer Union (NCU) was founded in 1949 to enhance collaboration between the cancer societies in the Nordic countries. Its main aim is co-operation on relevant strategic issues, exchange of experiences, and to be a forum for inspiration for the Danish Cancer Society, the Faroe Cancer Society, the Cancer Society of Finland, the Icelandic Cancer Society, the Norwegian Cancer Society and the Swedish Cancer Society.

The NCU is directed by a board comprising representatives of each of the member organizations. The chairmanship of the board is responsible for the NCU's function during a three year mandate period. The strategies and priorities for the NCU are stipulated by the board and should be valid during the three year alternating chairmanship of the member organizations. The Icelandic Cancer Society chairs the NCU Secretariat from 2015 to 2018.

In 2016 the Icelandic Cancer Society, through chairmanship of the NCU, coordinated activities within the NCU and convened four joint NCU board meetings. These meetings were held in Oslo in Norway in February 2016, in Reykjavík in Iceland in May 2016, in Gustavelund in Finland in September 2016, and in Copenhagen in Denmark in November 2016. In March 2016, additionally, a working group to revise the statutes of the NCU met in Copenhagen. The meeting in Finland was in conjunction with an ANCR (Association of Nordic Cancer Registries) and NCU joint symposium.

In February, new general guidelines for the application for NCU strategic funds were adopted by the board, which promote more involvement of the board in initiating strategic projects. To follow up the use of strategic funds a report of the activities of the Summer School for Cancer Research and of NORDCAN was presented to the board, as well as reports for other smaller projects.

A new version of the statutes of the NCU was adopted in May 2016, which was considered more in line with the current views and practice.

In May 2016 The NCU board adopted a declaration along the lines of the World No Tobacco Day, which had been prepared by Kreftforeningen in Norway. A joint decision was made by all

members to translate the declaration and introduce the concept through media coverage in the individual countries.

The European Cancer League (ECL) is a pan-European umbrella organisation of national and regional cancer leagues. In collaboration with other members of the ECL, the NCU contributed to issue of the Declaration of Intent by the European Task Force regarding the Equal Access to Cancer Medicines. This declaration was discussed by the Board. All of the countries involved are in agreement with the declaration and emphasize the importance of collaboration to ensure access to the best medicines available for cancer patients.

A draft of The Icelandic Cancer Plan for the period 2016-2020 was introduced at the Board meeting in Reykjavík in May 2016. This plan is in line with the cancer plans in the other Nordic countries. The countries compared the strengths and weaknesses of the cancer plans in the Nordic countries in November, and shared information on the current status and future plans.



At the end of the NCU meeting in May 2016, the president of Iceland, Mr. Ólafur Ragnar Grímsson, invited the board of NCU and those working on its behalf in Iceland to a reception at Bessastaðir.

Cancer Research UK presented their work at our meeting in Finland, and proposed collaboration with the NCU. Following the meeting the CRUK submitted information to the NCU board to be shared within the Nordic countries.

Representatives from Aalands Cancer League attended the NCU board meeting in November, and

shared information of their work and obtained information of the work of the NCU and of the member organizations.

Cancer screening in the Nordic countries was discussed, and the different approaches compared to some extent. Status of avoidable cancer research by NORDCAN was presented as well as other issues, e.g. immigration and cancer, cancer registration issues, cancer research and genetics in Iceland.

Every year the Nordic Cancer Union grants € 750.000 to cancer research. In 2016 the NCU awarded 16 grants totalling € 750.000 to cancer research. Grants ranged from € 40.000 to € 60.000.

The total income of the NCU in 2016 was € 1.080.446. Membership fees accounted for € 1.077.863, financial income for € 302 and the refund from the Nordic summer school accounted for € 2.263. Total operating costs (staff included) were € 873.132.

The purpose of the NCU research grants is to support and stimulate collaborative Nordic research that will benefit cancer patients in the Nordic countries. By funding high quality research, the NCU aims to achieve improved knowledge and understanding of cancer diseases, their effective prevention, treatment and/or rehabilitation.

At the core of the work of the NCU is the sharing of experiences and ideas. Reports from each country at each board meeting are thus probably the most important aspect of the work, and the NCU forum in 2016 served the member organizations well and was inspirational,- as always.

### **Representatives in the NCU meetings 2016:**

#### **Denmark**

Dorthe Gylling Crüger, Chairman of the Danish Cancer Society, Leif Vestergaard Pedersen, Managing director, Elizabeth Hjorth, Head of Office and Hans Henrik Storm, Medical Vice Director;

#### **Finland**

Sakari Karjalainen, Secretary General and Carita Åkerblom, Secretary of Organizational Affairs;

#### **Faroe Islands**

Durita Tausen, Chairman of the Faroese Cancer Society;

#### **Norway**

Ole Alexander Opdalshei, Assisting General Secretary and Kirsten Haugland, Head of Research and Prevention;

#### **Sweden**

Ulrika Årehed Kågström, General Secretary and Suzanna Wärn, Responsible for Strategic Coordination;

#### **Iceland**

Ragnheiður Haraldsdóttir, NCU Chairman, Kristján Sturluson, Director of the Icelandic Cancer Society and Ingimar Einarsson, NCU Coordinator.



# NCU Approved Research Grants 2016

## The Scientific Committee

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

Members of the scientific committee in 2015-2018 are: from Iceland: Thorunn Rafnar, chairman of the committee, biologist and Phd, works at Cancer Decode Genetics; from Denmark: Elsebeth Lynge, professor and mag.scient.soc; from the Faroe Islands: Johan Poulsen, physician and urologist; from Finland: Klaus Peter Elenius, Phd and professor of medical biochemistry; from Norway: Kristina Kjørheim, Chief and Deputy Head of Department for Research in Cancer Registry; from Sweden: Klas Kärre, Phd and professor in molecular immunology.

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

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

## NCU grant applications 2016

The Nordic Cancer Union received 34 grant applications in 2016. The annual NCU Scientific Committee meeting was conducted in Copenhagen on November 22<sup>nd</sup> 2016. The committee recommended that 16 projects were granted funding by the NCU Board. A list of the projects for which funding was recommended is presented below. The committee's assessment is based on scientific quality, quality of researchers, level of Nordic synergy, and relevance to NCU's strategy.

Table 1 provides an overview of the number of applications received and the level of funding granted (if approved by the NCU board) from 2013 to 2016.

**Table 1: Number of applications and level of funding granted**

	2016	2015	2014	2013
Number of applications received	34	41	35	42
Number and ratio (%) of applications funded	16 (47 %)	16 (39 %)	15 (42.9%)	17 (40.5%)

Total amount of funding applied for (€)	3 221 733	3 203 311	3 727 851	4 724 228
Total amount of funding applied for – successful applications (€)	1 536 475	1 217 679	1 292 080	1 863 571
Total funding granted (€)	750 000	750 000	750 000	750 000
Ratio of funding received to amount applied for – successful applications (%)	48%	62 %	58 %	40 %

### **Conflict of interest in the evaluation process**

The chairman of the scientific committee assigned 6 in-depth evaluation tasks to each of the committee members. One member declared partiality for three in-depth evaluation tasks and a second member declared partiality for two in-depth evaluation tasks and these were reassigned. In the case of general evaluations two members declared partiality for four to six applications and one member declared partiality for one application. “Conflict of interests” was registered instead of evaluation scores.

During the evaluation meeting, committee members did not participate in evaluation of applications in which they had declared partiality. The committee members left the room if they had declared partiality. This was the case in a total of eleven applications in 2016. It is also worth mentioning that one of the committee members also was an applicant this year.

### **Quality of applications**

The number of applications was in the lower range compared to previous years (2016:34, 2015:41, 2014:35, 2013:42, 2012:30, 2011:41). In general the committee found the quality of applications to be good, but still some applications fail to fulfill the formal criteria.

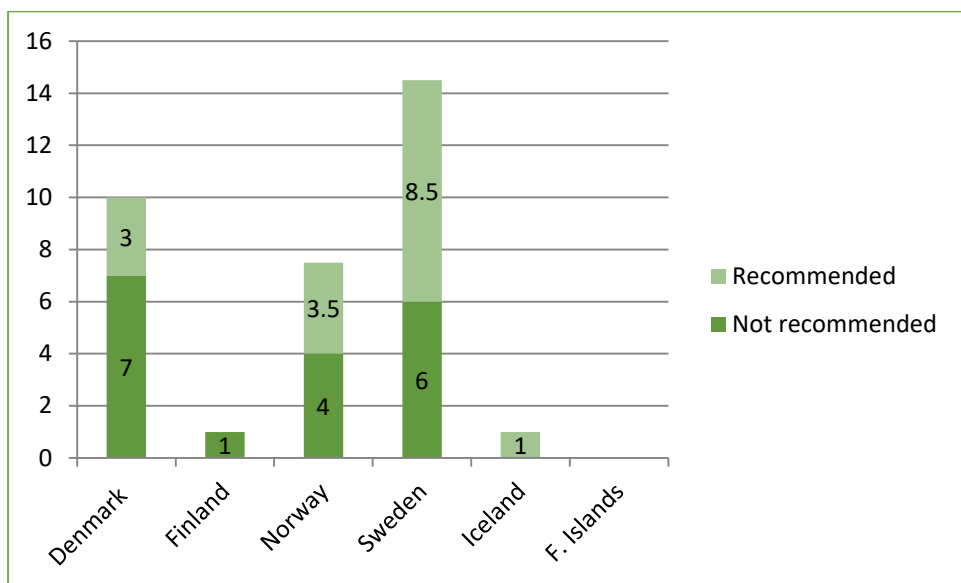
NCU received applications for 6 on-going and 28 new projects. scientific committee recommended 6 on-going and 10 new projects for funding in 2016. Two of the new projects recommended for funding are highlighted as examples of high-quality research; one primarily clinical (Anna Bill-Axelsson) and one register based (Björn Pasternak), see table 2.

### **LOCATION OF PRINCIPAL INVESTIGATOR**

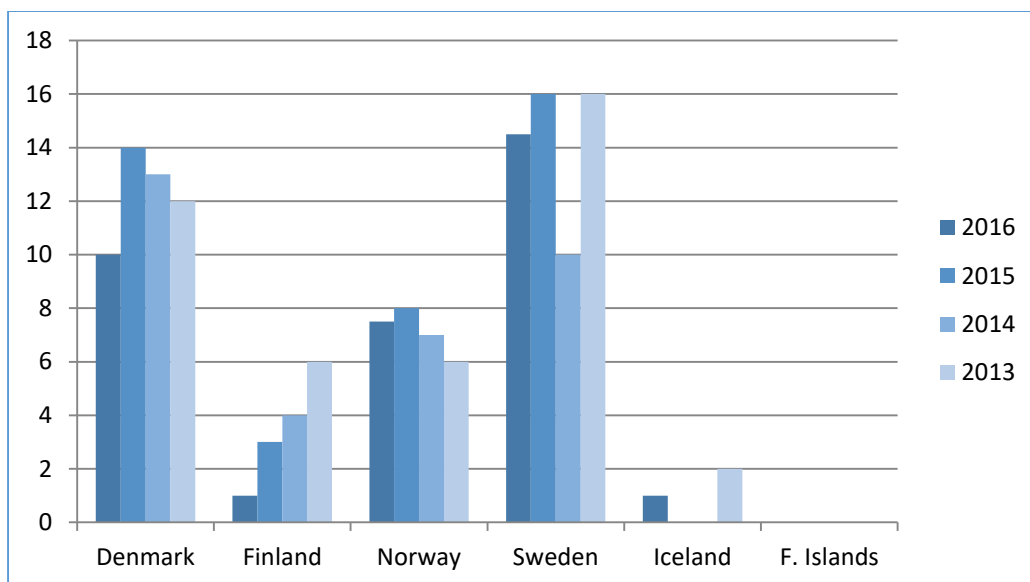
Figure 1 shows the number of applications from each of the Nordic countries in 2016 (determined by the workplace location of the principal investigator). Figure 2 shows the total number of grant applications received by the NCU from 2013 to 2016. Figure 3 shows each location’s share of the recommended applications (determined by the workplace location of the principal investigator).

***Figure 1: Number of applications (recommended and not recommended) by location in 2016***

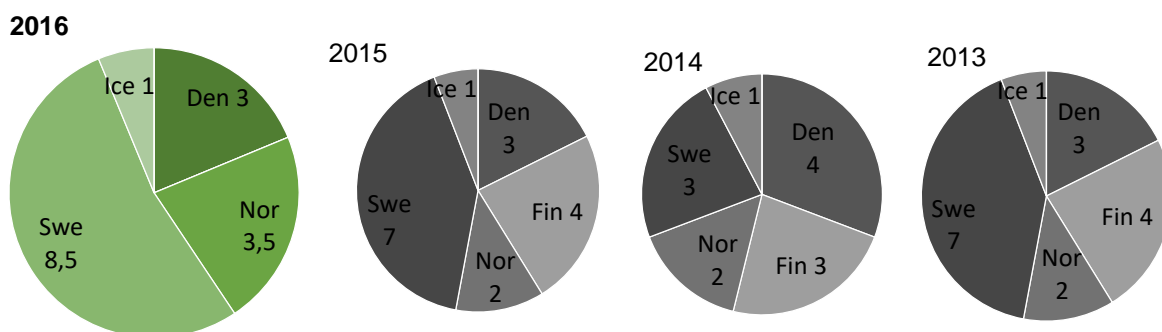




**Figure 2: Total number of applications by location from 2013 to 2016**

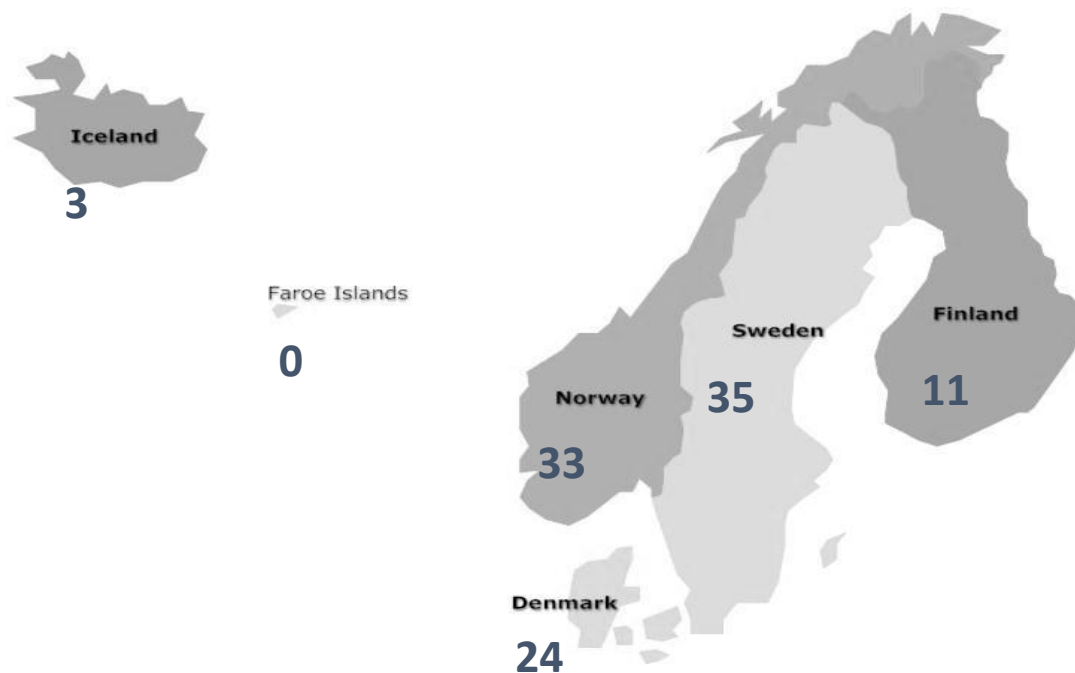


**Figure 3: Share of recommended applications by location from 2013 to 2016**



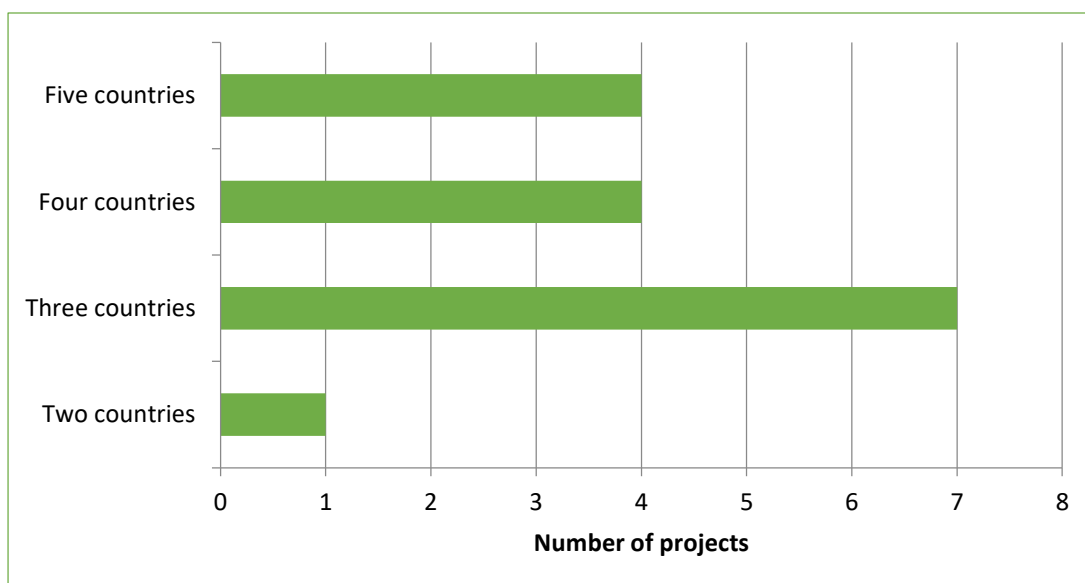
## NORDIC COLLABORATION

Collaboration is at the heart of the Nordic Cancer Union. The numbers in Figure 4 refer to all researchers, principal investigators and co-applicants, listed as participants in the projects for which funding is recommended. The specific Nordic country alliances for each project can be seen in the project overview.



*Figure 4: Project participants per location*

*Figure 5: Number of Nordic countries involved in projects for which funding is recommended*



At least two Nordic countries must be involved in research funded by the NCU. Figure 5 shows the number of countries involved in the projects recommended for funding in 2016 (defined by the work place location of the researchers participating in the project).

**Table 2: Projects recommended to the NCU Board for funding in 2016**

Principal investigator	Project title	Project workplace (principal investigator)	Applied amount	Recommended amount	Nordic countries involved
Akre, Olof	SPCG-15: Surgery versus radiotherapy for locally advanced prostate cancer: a randomised clinical trial	Karolinska Institutet	€ 50 000	€ 50 000	Den, Fin, Nor, Swe
Bill-Axelsson, Anna	SPCG-17: Prostate Cancer Active Surveillance Trigger Trial (PCASTT)	Uppsala University, Akademiska Hospital	€ 291 389	€ 65 000	Den, Fin, Swe
Brown - for the Nordic Lymphoma Group, Peter de Nully	clinical trial-based precision medicine in the Nordic countries for patients with aggressive lymphomas	Rigshospitalet	€ 70 000	€ 40 000	Den, Fin, No, Swe
Giwerzman, Aleksander	The impact of testicular cancer and its treatment on the health of the offspring	Dept. of Translational Medicine, Lund University	€ 99 000	€ 40 000	Den, No, Swe
Grønberg, Bjørn H.	A Randomized Phase II Study Comparing Two Schedules of Hyperfractionated Thoracic Radiotherapy in Limited Disease Small-Cell Lung Cancer	Norwegian University of Science and Technology and St. Olavs Hospital - Trondheim University Hospital	€ 79 000	€ 65 000	Den, No, Swe
Harris, Jennifer	Genetic Epidemiology and Familial Risk of Cross-Cancer Associations: A Nordic Twin Study	The Norwegian Institute of Public Health	€ 109 000	€ 40 000	Den, Fin, No, Swe
Hellström Lindberg, Eva	Nordic Collaborative Clinical Database Initiative and Allogeneic Stem Cell Transplantation Project for Myelodysplastic Syndromes	Karolinska Institutet, Dept of Medicine, Karolinska University Hospital	€ 70 000	€ 40 000	Den, Fin, No, Swe
Jakola, Asgeir S.	Disulfiram response as add-on to chemotherapy in recurrent glioblastoma: A randomized controlled trial	Sahlgrenska and St. Olavs Hospital	€ 75 000	€ 40 000	Den, No, Swe
Jonsson, Håkan	Estimation of overdiagnosis in breast cancer screening	Umeå University	€ 175 262	€ 50 000	Den, Fin, No, Swe
Lagergren, Jesper	Antireflux surgery and cancer risk in the Nordic Antireflux Surgery Cohort (NordASCo)	Karolinska Institutet, Stockholm	€ 70 780	€ 40 000	Den, Fin, No, Swe, Ice
Li, Jiong	Maternal diseases during pregnancy and childhood leukemia in the offspring: a cohort study in 8 million children in five Nordic countries	Aarhus University	€ 70 000	€ 50 000	Den, Fin, No, Swe, Ice
Lyng, Elsebeth	Impact of screening on cancer incidence trends and age-patterns	University of Copenhagen	€ 59 000	€ 50 000	Den, No, Swe
Pasternak, Björn	Cancer risk associated with new glucose-lowering drugs: a joint register-based cohort study in Sweden, Denmark, and Norway	Karolinska Institutet	€ 64 844	€ 65 000	Den, No, Swe

Stocks Charles, Tanja	Metabolic traits, tobacco smoking, and bladder cancer risk; a study on biological interactions in relation to low- and high-risk disease	Lund university	€ 56 200	€ 40 000	No, Swe
Tryggvadóttir, Laufey	Prognostic Factors, Treatment and Breast Cancer Survival in Nordic BRCA2 Mutation Carriers	University of Iceland, Sæmundargötu 2, 101 Reykjavik; Icelandic Cancer Registry, Skogarhlid 8, 105 Reykjavik	€ 70 000	€ 50 000	Den, Fin, No, Swe, Ice
Valberg, Morten	Improved estimation of familial cancer risks: Utilizing modern statistical methods	Department of Biostatistics, Institute of Basic Medical Sciences, University of Oslo	€ 127 000	€ 25 000	Den, No, Swe
<b>Total</b>			<b>€ 1 536 475</b>	<b>€ 750 000</b>	

# Awarded grants 2016

Principal Investigator	Project Title	Project workplace (Principal Investigator)	Awarded amount (Euros)
Akre, Olof	SPCG-15: Surgery versus radiotherapy for locally advanced prostate cancer: a randomised clinical trial	Karolinska Institutet, Sweden	50.000
Bill-Axelsson, Anna	SPCG-17: Prostate Cancer Active Surveillance Trigger Trial (PCASTT)	Uppsala University, Akademiska Hospital, Sweden	65.000
Brown - for the Nordic Lymphoma Group, Peter de Nully	Clinical trial-based precision medicine in the Nordic countries for patients with aggressive lymphomas	Rigshospitalet, Denmark	40.000
Giwerzman, Aleksander	The impact of testicular cancer and its treatment on the health of the offspring	Dept. of Translational Medicine, Lund University, Sweden	40.000
Grønberg, Bjørn H.	A Randomized Phase II Study Comparing Two Schedules of Hyperfractionated Thoracic Radiotherapy in Limited Disease Small-Cell Lung Cancer	Norwegian University of Science and Technology and St. Olavs Hospital - Trondheim University Hospital, Norway	65.000
Harris, Jennifer	Genetic Epidemiology and Familial Risk of Cross-Cancer Associations: A Nordic Twin Study	The Norwegian Institute of Public Health, Norway	40.000
Hellström Lindberg, Eva	Nordic Collaborative Clinical Database Initiative and Allogeneic Stem Cell Transplantation Project for Myelodysplastic Syndromes	Karolinska Institutet, Dept of Medicine, Karolinska University Hospital, Sweden	40.000
Jakola, Asgeir S.	Disulfiram response as add-on to chemotherapy in recurrent glioblastoma: A randomized controlled trial	Sahlgrenska and St.Olavs Hospital, Norway	40.000
Jonsson, Håkan	Estimation of overdiagnosis in breast cancer screening	Umeå University, Sweden	50.000
Li, Jiong	Maternal diseases during pregnancy and childhood leukemia in the offspring: a cohort study in 8 million children in five Nordic countries	Aarhus University, Denmark	50.000

Pasternak, Björn	Cancer risk associated with new glucose-lowering drugs: a joint register-based cohort study in Sweden, Denmark, and Norway	Karolinska Institutet, Sweden	65.000
Lagergren, Jesper	Antireflux surgery and cancer risk in the Nordic Antireflux Surgery Cohort (NordASCo)	Karolinska Institutet, Sweden	40.000
Lyng, Elsebeth	Impact of screening on cancer incidence trends and age-patterns	University of Copenhagen, Denmark	50.000
Stocks Charles, Tanja	Metabolic traits, tobacco smoking, and bladder cancer risk; a study on biological interactions in relation to low- and high-risk disease	Lund University, Sweden	40.000
Tryggvadóttir, Laufey	Prognostic Factors, Treatment and Breast Cancer Survival in Nordic BRCA2 Mutation Carriers	University of Iceland and Icelandic Cancer Registry, Skogarhlid 8, Iceland	50.000
Valberg, Morten	Improved estimation of familial cancer risks: Utilizing modern statistical methods	Department of Biostatistics, Institute of Basic Medical Sciences, University of Oslo, Norway	25.000
<b>Total</b>			<b>750.000</b>



# Strategic Funds

The Nordic Cancer Union provides funding for projects of high standard within the field of cancer amounting to 250.000 euros annually. The projects funded by the NCU meet strict requirements, with priority given to projects and initiatives that reflect the current general strategy of the NCU and have added Nordic value.

New regulation and guidelines were adopted by the board of the Nordic Cancer Union in 2016, and came into use immediately.

Researchers working in two or more Nordic countries must be involved in the project. The projects applied for must have cancer relevance, be uniquely suited to be carried out within the Nordic countries, and the effect of collaboration should be synergistic.

The projects funded in 2016 were NORDCAN, Nordic NECT and UICC/IARC Summer School, as can be seen from the following table.

## **Confirmed financial support 2016**

Secretariat for Nordic NECT	50.000 euros
UICC/IARC Summer School	16.400 euros
NORDCAN	35.500 euros
Total confirmed support	101.900 euros

## Strategic projects overview

Project overview - Stockholm 17 February 2017, All amounts in EURO

	Notes	Total support	Planned in 2015	Planned in 2016	Planned in 2017	Planned in 2018	Planned in 2019
<b>Confirmed financial support</b>							
Secretariat for Nordic NECT .....	1	148.000	48.000	50.000	50.000		
UICC/IARC summer school .....	2	49.200	16.400	16.400	16.400		
NORDCAN .....	3	106.500		35.500	35.500	35.500	
Nordic Summer School in Cancer Epidemiology .....	4	92.300			46.150	46.150	
<b>Total confirmed support</b>		<b>396.000</b>	<b>64.400</b>	<b>101.900</b>	<b>148.050</b>	<b>81.650</b>	<b>0</b>
<b>Actual payments</b>							
		<b>Total support</b>	<b>Actual payments 2015</b>	<b>Actual payments 2016</b>	<b>Actual payments 2017</b>	<b>Actual payments 2018</b>	<b>Actual payments 2019</b>
Secretariat for Nordic NECT .....	1	148.000					
UICC/IARC summer school .....	2	49.200	13.227				
NORDCAN .....	3				71.000		
Nordic Summer School in Cancer Epidemiology .....	4				92.300		
<b>Total actual payments</b>		<b>197.200</b>	<b>13.227</b>	<b>0</b>	<b>163.300</b>	<b>0</b>	<b>0</b>

### Notes:

1. Confirmed on a Board Meeting in Helsingör in September 2015
2. Confirmed on a Board Meeting in Reykjavik 22 May 2015
3. Confirmed on a Board Meeting in Oslo 19 February 2016
4. Confirmed on a Board Meeting in Copenhagen 25 November 2016

	Notes	Total support	Planned in 2015	Planned in 2016	Planned in 2017	Planned in 2018	Planned in 2019
<b>Unpaid confirmed financial support</b>							
Secretariat for Nordic NECT .....	1	148.000	48.000	50.000	50.000		
UICC/IARC summer school .....	2	49.200		16.400	16.400		
NORDCAN .....	3	106.500				35.500	
Nordic Summer School in Cancer Epidemiology .....	4	92.300					
<b>Total confirmed support</b>		<b>396.000</b>	<b>48.000</b>	<b>66.400</b>	<b>66.400</b>	<b>35.500</b>	<b>0</b>

# The Danish Cancer Society

## *Kræftens Bekæmpelse*

**Managing Director**  
**President of the Board**

**Leif Vestergaard Pedersen**  
**Dorthe Gylling Crüger**

### **Structure of the Organization**

The Danish Cancer Society was founded in 1928 and is a democratic organization with 417.000 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.

688 people are employed by the Danish Cancer Society within research, patient support and prevention/information. The number of volunteers is app. 32.000.

### **Income and Costs**

As far as concerns fundraising and income 2016 was a successful year. The Danish Cancer Society's income was 96.192.000 euros. Gifts accounted for 64.730.000 euros, legacies for 19.717.000 euros, and subsidies for 3.707.000 euros and others accounted for 8.037.000 euros.

Total operating costs (staff included) were 85.926.000 euros.

In 2016, the Danish Cancer Society distributed costs on the following target areas: Research 52.846.000 euros, prevention: 13.357.000 euros, cancer patients care: 16.881.000 euros and other activities: 2.842.000 euros.

### **Political activities**

#### ***Cancer Plan IV***

The Danish Cancer Society welcomed the 4<sup>th</sup> Cancer Plan since 2000 in the fall of 2016. The Danish government allocated cumulative 2,2 billion DKK to new initiatives to tackle the cancer burden until 2020. Cancer Plan IV sets out three national targets;

- Survival of cancer in Denmark in 2025 at the same level as the best of our Nordic neighboring countries.
- In 2030 there is a smoke-free generation of children and young people.

- 90 pct. of cancer patients will in 2020 experience to have a patient-responsible physician.

The Cancer Plan also sets out initiatives to strengthen quality of cancer treatment to e.g. develop clinical guidelines and education and training for cancer surgeons. Furthermore the Cancer Plan supports rehabilitation and palliative care. Initiatives to build up early diagnosis continue and in 2017 a service check of The Danish Cancer Pathways will begin.

### ***DCCC- Danish Comprehensive Cancer Centre***

The Danish Cancer Society, Danish Universities and leading cancer researchers, The Association of Medical Specialists and Danish Regions (regional governments association) joined forces to make Denmark an even more attractive country for cancer research. The parties agreed to establish DCCC on a national basis collaborating all existing high-level cancer research institutes, universities and clinical oncology into a virtual organisational structure with an executive board and a scientific committee. The aim is to improve cancer treatment and introduce new treatment breakthroughs as early as possible in the clinics. The Government prioritised with Cancer Plan IV the establishment of a DCCC, and allocated resources to coordinate and implement national research and clinical initiatives.

### ***Patient responsible doctor***

The Danish Cancer Society and The Association of Medical Specialists worked together for nomination of a patient responsible doctor to oversee and take overall responsibility for the overview for each cancer patient through all the treatment phases. The patient responsible doctor will support and give the patients the experience of correlation, coordination and security in his/her course of disease. The patient should know the name of the doctor who takes the overall responsibility for his/her diagnosis and treatment. With Cancer Plan IV the Government has prioritised that the regions implement patient responsible doctors and the Government has subsequently entered into an agreement with the Danish Regions and all involved parties including the Danish Cancer Society, about the role and duty of the patient responsible doctor.

### ***Tobacco Free Portfolios/Bronwyn King: de-vesting in tobacco industry.***

The Danish Cancer Society has been inspired by and does collaborate with Tobacco Free Portfolios/Bronwyn in activities encouraging finance sector to de-vest in tobacco industry. Tobacco Free Portfolios is currently working with more than 100 financial institutions including Sovereign Wealth Funds, pension funds, insurers, banks and fund managers. The Danish Cancer Society and Tobacco Free Portfolios collaborate to convince the Danish finance sector acknowledge the health challenge caused by tobacco and avoid investments in the tobacco industry.

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

The Danish Cancer Society Research Center (DCRC) was established on 1 January 2012 as a merger between the Institutes of Cancer Biology and Cancer Epidemiology. The Center, which holds a dynamic, international and competitive research environment spanning basic, translational, epidemiological and clinical aspects, employs some 225 researchers and technicians and a varying number of scholars and guest researchers. The DCRC is furnished with modern office facilities, fully equipped laboratory space including access to state-of-the-art machinery and animal house.

The scientific work of DCRC is organized within eight Research Units and three Junior Groups:

***Diet, Genes and Environment*** headed by prof. Anne Tjønneland, ***Virus, Lifestyle and Genes*** headed by prof. Susanne Krüger Kjær, ***Cell Death and Metabolism*** headed by prof. Marja Jäätelä, ***Genomic Integrity*** headed by prof. Jiri Bartek, ***Survivorship (SVP)*** headed by prof. Christoffer Johansen, ***Cell Stress and Survival*** headed by prof. Francesco Cecconi, ***Translational Cancer Research*** headed by prof. Nils Brünner, and ***Statistics and PharmacoEpidemiology*** headed by chief statistician Klaus Kaae Andersen. In addition, the Center holds three Junior Groups headed by Petra Hamerlik (***Brain Tumor Biology Group***) and Marin Barisic (***Cell Division Laboratory***) and Elena Papaleo (***Computational Biology Laboratory***). The latter supply the entire Center with bioinformatics support.

The total amount of external research grants allocated to DCRC in 2016 was 78 million DKK equivalent to some 10½ million EUR. Some 300 publications were published during the year, the vast majority in major scientific journals with global circulation (see also link below). In 2016, a senior DCRC researcher received the prestigious Nordic Fernström Prize, and two junior researchers were allocated the Sapere-Aude Prize from the Danish Research Council and one of Fellowship issued by Lundbeckfonden, both prizes (and accompanying grants) being among the finest distinctions in Danish research.

Below we shortly describe some of the many results published during 2016:

Among the many results published in 2016 are new knowledge on the genetic background of glioblastoma, drugs for treatment of allergy may enhance the action of chemotherapy and women with breast cancer and depression have improved survival if given extra support.

An updated research strategy for the Center for the period 2017-2019 was finalized in 2016 and is available on: <https://www.cancer.dk/dyn/resources/File/file/4/6294/1492756525/dcrc-2017-19-strategy.pdf>

More details regarding DCRCs research activities, including a full list of publications for 2016 can be found on: <http://www.cancer.dk/research>

## **Documentation & Quality**

Data driven quality improvement is our key objective in Documentation & Quality. Based on valid, timely and comprehensive data we work to push and support innovation and enhancement of Danish cancer care. Through documentation and research, we support improvement of cancer patients' survival, quality of life, safety and experiences with the Danish health care system including more and more their involvement in their own therapies.

Our activities in 2016 include most of them on an ongoing basis:

- Strategic partnerships with regions and hospitals on patient involvement, including shared decision making and Patient Reported Outcome Measures (PROMs)
- Hosting NORDCAN secretariat
- Updating cancer statistics
- National, representative surveys on cancer patients' experiences with cancer care in Denmark, preparing 2016 the launch of a survey in 2017 with 10.000 newly diagnosed cancer patients
- Studies of geographic variation in surgical outcomes in cancer care and similar studies to identify reasons for low cancer survival in Denmark
- Data and inputs to our new Cancer Plan IV

- Extending our Cancer register with clinical activity and quality data
- Professional advice to internal and well external stakeholders, e.g. the notion of the Patient Responsible Doctor or common ‘agreements with GPs’.
- We participate in several international benchmarking projects, ECL initiatives, e.g. Access to Medicines, and InterReg projects.

## **Patient Support & Community Activities**

The Danish Cancer Society has finished the building of six modern counselling centres near the large oncology centres in Denmark, and is currently planning a new counselling centre at Herlev Hospital in 2017. The counselling centres follow a new concept combining modern architecture and walk in counselling services with focus on empowerment of patients. The centres offer information, psychosocial support from professionals and volunteers, support groups, advice on social rights, exercise etc. Among the activities are physical training sessions for cancer patients during treatment as part of early rehabilitation in collaboration with the treating hospital. An evaluation among users has shown a high satisfaction with the services and the access to the centres. Male users and less educated users have increased in number. As part of these efforts, new interactive digital tools are used. In 2016:

- The telephone counselling service 'Kræftlinjen' has started on line video counselling to supplement telephone counselling.
- A model for the counselling centres to offer support and social networks for men with cancer was implemented in 13 counselling centres.
- Navigator project; more than 100 volunteers are educated to support socially vulnerable cancer patients during treatment and rehabilitation and the project implemented in 10 counselling centres.
- Intensified support to young cancer patients with peer visits to young patients in cancer treating hospitals.
- Digital panel of approx. 1300 patients and relatives are asked regularly about their experiences and opinion.
- Patient representatives are appointed to scientific committees and working groups.

## **Cancer Prevention & Information**

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

In collaboration with the Danish foundation TrygFonden we continued the campaign ”Fuld af liv”, which aims at reducing alcohol consumption among kids, teenagers and young adults .

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

In collaboration with the Danish foundation TrygFonden we continued the “Sun Safety” campaign. The aim is to prevent skin cancer by teaching the Danes how to protect themselves from the sun and to avoid sunbed use.

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

Forty-seven pct. of the Danish population are currently overweight, and that number increases continuously. Overweight, including poor diet and lack of physical activity, ranks second among



risk factors causing cancer in Denmark, and overweight is associated with eleven documented types of cancer. Approximately 50.000 cases of cancer are preventable until 2045, if we can eliminate overweight in the Danish population, and additionally, normal weight patients suffering cancer have a better survival rate than patients that are overweight.

In 2016, we concluded the project Activating Schoolyards (In Danish: Drøn på skolegården) designed to increase physical activity by redesigning schoolyards to appear applicable for teaching combined with physical activity. We continued working on the project Play and Learn (In Danish: Leg på streg) in 2016. This project offers a simple and cheap opportunity to sketch predetermined lanes for active learning in already existing schoolyards.

In 2016, we concluded a successful collaboration with the University of Copenhagen, TrygFonden and REMA 1000 involving shelf management, redesigning the weekly brochures offers to promote healthier products and reformulating processed food in order to reduce the amount of calories sold. In 2015, The Danish Cancer Society in collaboration with REMA 1000 successfully reduced the calorie sales among the Danish population by 27.3 billion (equivalent to at 5 % reduction) without reducing turnover. Link to report (in Danish): <https://www.cancer.dk/dyn/resources/File/file/5/5815/1474888741/letindkoebet.pdf>

### ***HPV vaccination***

Denmark has the highest prevalence of cervical cancer among the Nordic countries. Each year, approximately 375 women in Denmark get cervical cancer and about 100 women die of the disease. Due to negative publicity in the media, based on reports of girls who believe they have adverse effects of the vaccine, there has been a dramatic drop in participation in the HPV vaccination programme. Among other initiatives, we performed qualitative interviews and a survey among parents of girls aged 10-14 years of age. We also opened a telephone hot-line in 2016, where parents and others can call and get information about HPV vaccination.

### ***Screening for cervical cancer***

In Denmark, the participation rate in the cervical cancer screening programme is only about 75 pct. We work in different ways to increase this rate to at least 85 pct.

In 2016 we launched a short campaign, “An invitation letter of great importance” including postcards distributed to cafés around the country and movies on Facebook focusing on the invitation letter and the importance of making an appointment with the GP when receiving the invitation. In only two weeks, the film had a reach of about 300.000 views on FacebookLink to the film: “[An invitation letter of great importance](#)”

### ***Campaign about symptoms of cancer – “The 7 signs of cancer”***

2016 was the second year of the “7 signs of cancer”, a campaign about symptoms of cancer by the Danish Cancer Society. The aim of the campaign is to make Danes aware of specific cancer symptoms – so they consult their GP in time. The main target group is men and people with lower education, 50+.

### ***Smoking***

Smoking is still the greatest avoidable risk factor for cancer in Denmark. Smoking is the cause of every third cancer death in Denmark. In 2016, 21 percent of all adults (15+) smoked. Sixteen percent were daily and five percent occasionally smokers. The proportion of smoke-free homes

increased: More than 90 percent of homes with children are now totally smoke-free home. In 2010, the number was only 70 percent.

A partnership was established in 2016 with the Danish foundation TrygFonden for a smoke-free future. The goals are max. five percent adult smokers in 2030 and no children smoking in 2030. In September 2016, we launched a new version of the app Xhale which helps young people quit smoking. Xhale delivers on-the-go assistance through a personalized experience with push messages, films, a blog and exercises. The app Xhale was one of the World Summit Award Winners 2016 in the category Health & Well Being.

*You can read the detailed annual report 2016 from the Danish Cancer Society here:*  
[http://pdf.cancer.dk/Nyheder/aarsberetning/2016-annual-report/?\\_ga=2.161989370.736441742.1505766906-1060028783.1471423898](http://pdf.cancer.dk/Nyheder/aarsberetning/2016-annual-report/?_ga=2.161989370.736441742.1505766906-1060028783.1471423898)

# 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 organization comprising 18 member organizations (12 regional societies and 6 national patient organizations).

The CSF maintains the Finnish Cancer Registry and the Mass Screening Registry, which is part of the Cancer Registry. CSF also handles the administrative duties of the Cancer Foundation Finland (est. 1948).

### **Income**

The income of the Society was 8.422.596 euros in 2016. Biggest sources of income were gifts 2.659.000 euros, legacies 1.168.275 euros, subsidies 1.736.000 euros and others 5.515.662 euros.

Total operating costs (staff included) were 8.081.163 euros.

In 2016, the Society distributed costs on the following target areas: research 1.838.798 euros, prevention 1.168.275 euros cancer patient care 494.056 euros and others 2.896.627 euros.

### **Main fields of activity**

The main fields of activity of the Cancer Society of Finland are:

- In the role of a patient organization
  - advocacy
  - counselling
  - peer support
  - rehabilitation and recreation for cancer patients
  - volunteer work (besides peer support)
  - website, magazine, other communications
- In the role of a public health organization
  - influencing national cancer policies (e.g. national cancer control, tobacco and alcohol policies)

- health promotion
- collaboration with other patient and public health organizations
- website and media services
- In the role of an expert organization of cancer control
  - statistics on cancer incidence, mortality and cancer patient survival
  - epidemiological and statistical research
  - supporting the national screening programs of cancer (quality assurance e, research and planning)
  - website and media services

### **Highlights in 2016**

In 2016, the CSF celebrated its 80<sup>th</sup> Anniversary. The focus and theme of the celebrations were volunteers at all levels and all kinds of activities. Each member organization awarded one volunteer (a person or a group) to lift up and respect the commitment of all volunteers. As a part of the CSF's development plan (A strong and competent NGO) a plan to develop the role of volunteers was prepared.

The advocacy work for national cancer policy was active. The CSF implemented its Strategy 2020 in the form of seven flagship projects.

### **Advocacy and lobbying**

The CSF took a lot of activities to influence actively national health and social policies, especially in the field of cancer control. As a key goal, the establishment of a national comprehensive cancer center was promoted. Together with other NCD organizations the CSF influenced on the preparation of the new tobacco and alcohol legislation. The CSF was represented in several key government working groups preparing cancer control policies (e.g., national cancer center, national screening policies, health promotion).

### **Health promotion**

For already 16 years, one of the central focus areas of the CSF's health promotion work has been actions that aim at preventing young people from starting smoking or using snuff (snus) or e-cigarettes and encouraging them to quit. The CSF succeeded in revealing the routes of smuggling of snus from Sweden to Finland. The CSF has been especially worried about the increased use of snus among minors. All use of snus among minors is illegal.

Promoting sun protection is another spear activity. In 2016 the campaigning continued to focus especially on young people with outdoors summer jobs. The campaign approached employers hiring youth to work outside.

Other areas of health promotion include alcohol, diet, sedental life style and obesity.

### **Counselling services, rehabilitation and peer support**

The Cancer Society's counselling services comprise of a national counselling service and regional counselling services. Counselling is always provided by health care professionals. The national counselling services had 5–6 specialized nurses and there were a total of 50 counsellors with similar training working for regional societies in 2016. The patient organizations also provide counselling.

The Cancer Society and its member associations developed rehabilitation services and offered peer support. In 2015 new models of peer support were piloted. All peer support volunteers are trained according to common standards.

### **Communication**

The Cancer Society of Finland's Communications is responsible for internal and external communication and the Cancer Foundation Finland's communication. Digital communication is growing stronger and necessitates new skills. The large-scale renewal of CSF's website started in 2015 and continued on into 2016. In 2016, the websites of 11 member organizations were renewed in the same manner. The most central printed communication channel is the Syöpä-Cancer-magazine, which is published in Finnish and Swedish and has circulation of 115 000 copies and 5 500 for the Swedish version.

### **The Finnish Cancer Registry**

The Finnish Cancer Registry is a statistical and epidemiological research facility maintained by the CSF. The CSF also maintains the national cancer registry that includes mass screening registers of breast and cervix cancer.

The registry's work responsibilities include pulling together cancer data with quality control, contacts to the notification sources, data management, information releasing, and documentation.

During 2016 several changes were made to improve database quality. Colon cancer coding was altered in regard of its geographic prevalence and all colon cancers since 2004 were sought and recoded.

### **International activities**

The Cancer Society and the Finnish Cancer Registry are active on European and global level. The CSF worked towards efficient Tobacco Products Directive with other health NGOs on European level. Secretary General of the CSF was President of the Association of the European Cancer Leagues. The CSF was a leader in two work packages of Joint Action Cancon, its outcome was the European Guide on Quality Improvement in Comprehensive Cancer Control and it was published in 2017. The Joint Action website is [www.cancercontrol.eu](http://www.cancercontrol.eu). The CSF is also leading one work package of the Joint Action on Rare Cancers (JARC).

### **Fundraising**

The Cancer Society of Finland and the Cancer Foundation Finland have agreed that fundraising activities are implemented through the Cancer Foundation Finland. The best know campaign is Pink Ribbon in October.

The Cancer Society and the Cancer Foundation Finland have a common strategy. Their boards meet jointly and they have the same Secretary General. They also have a common working committee and finance committee. The Cancer Foundation gave 5,5 million euros as Research Awards in 2016.

*You can read the detailed annual report from the Finnish Cancer Society, 2016 here:*  
<https://www.cancersociety.fi/organisation/the-cancer-society/action-plan-and-annual-report/>

Websites in English:

[www.cancersociety.fi](http://www.cancersociety.fi)

[www.allaboutcancer.fi](http://www.allaboutcancer.fi)



# The Faroese Cancer Society

## *Krabbameinsfelagið*

**Director**  
**Chairman of the Board**

**Jansy Gaardlykke**  
**Durita Tausen**

### **Structure**

The Faroese Cancer Society was founded in 1979 with the purpose to address the challenges of cancer in the Faroe Islands. A board of five members, which are elected at the annual General Assembly, governs the society. The main office is situated in Tórshavn, capitol of the Faroe Islands. Three employees are employed at the office, two of them part-time. A social worker is also affiliated with the society. The number of volunteers is approximately 40 people.

### **Income and costs**

The Faroese Cancer Society's total income in 2016 was 318.823 euros. Gifts accounted for 274.124 euros and others accounted for 44.699 euros.

Total operating costs (staff included) were 199.769 euros. In 2016, the Faroese Cancer Society distributed costs on the following areas: Prevention: 4.537 euros, cancer/patients care: 39.121 euros and on other activities: 10.773 euros.

### **Activities in 2016**

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.

### **Cycling for children with cancer**

Team Rynkeby has activities in Finland, Norway, Sweden, Australia and Denmark. In 2013, an agreement was made between Team Rynkeby, The Children's Cancer Fund and the Faroese Cancer Society, to bicycle to Paris in July 2014. The activity "Cycling for children with cancer" proved to be very successful and is now an annual event. In July 2016, a team of 50 bicycled to Paris. Some of them were the same as the previous years. The income of this activity goes to children with cancer and children diagnosed with life threatening lung and heart disease.

### **Walk half marathon**

In collaboration with the Tórshavn Marathon, the Faroese Cancer Society arranged a walking half marathon in June 2016. There were 197 participants walking. A donation fee of DKK 100 was

granted to the Faroese Cancer Society. The weather was perfect and the mood was great. The walkers were cheering the runners, so overall, it was a win-win situation. In September 2016, the Faroese Cancer Society in collaboration with Frælsi Ítróttarfelag arranged a walking half marathon on the island of Vágar. The 160 participants walked the beautiful scenic route from Gásadalur to Sandavágur.

### **Neighbourhood coffee**

Neighbourhood coffee has its origin in the question: “How can I help?” It uses what we are good at in the Faroes: showing hospitality, making the guests feel at home and dishing up a lot of cakes. The host invites neighbours, friends and family for a visit. They converse, arrange some entertainment or do something completely different. The guests decide what to pay. The result was 80 hosts and 62.760 €. A bigger income makes it easier to achieve the Cancer Society’s goal: to help and support cancer patients and their families, and to support cancer-research.

### **Art therapy for cancer patients**

The Faroese Cancer Society arranges regular courses in art therapy for cancer patients and former cancer patients.

### **Hair and skin care for women**

The Faroese Cancer Society and The Body Shop Faroe Island offer women with cancer undergoing chemotherapy and radiotherapy regular courses in facial and skin care.

### **Activities of Help groups**

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

The group has had many fruitful meetings in 2016. On the 4th of April 2016, the group arranged a seminar for “men only”. Renowned dr. PhD in urology Michael Borre, gave a lecture on prostate cancer, causes, genealogy and lifestyle. The group’s purpose is for men to come together to converse and support each other, to gather knowledge on prostate cancer, to inform on prevention and to arrange different events.

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

Self-help group “Bót til Bata” wants to reach as many women who have undergone surgery for breast cancer as possible. In 2016, the group arranged several meetings and lectures on the subject breast cancer.

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

The group has arranged courses and gatherings for people who suffer from pelvic cancer. The group arranged several meetings and lectures on the subject pelvic cancer.

#### **The Melanoma Group**

The group meets regularly for conversation, lectures and cosy get-togethers. The group continues to gather knowledge on melanoma, to provide better information on how to prevent skin cancer and melanoma.

#### **The Stoma Group**

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

### **Parents Group**

The Parents Group organized a Christmas party for families of children with cancer in December 2016. They also arranged a family weekend filled with activities for the children and parents.

### **Conversation groups**

The Society is constantly trying to adapt its offerings to the needs of patients and relatives. Conversation groups have been arranged for people who have lost spouses to cancer, groups for relatives and groups for children, whose parents suffer from cancer. The Society also offers 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 one another.

### **Statistics**

In 2016, 236 new cases of cancer were diagnosed in the Faroe Islands. Breast cancer is stable. The past nine years, there have been between 30 and 40 cases per year. Prostate cancer: 25 cases on average the last five years. Lung cancer: every year, around 17 people in the Faroe Islands get lung cancer. This figure is also stable. Colon cancer: 17 cases on average the last five years. It was a great achievement that the Faroese cancer statistics were registered in NORDCAN. Now you can use Faroese figures for comparison with those of the other Nordic countries.

*You can read the detailed annual report 2016 from the Faroese Cancer Society here:*

<http://www.krabbamein.fo/Files/Billeder/Nýggj%20heimasíða/PDF/Ársfrágreiðing%202016%20-%20Liðug.pdf>

# The Icelandic Cancer Society

## *Krabbameinsfélag Íslands*

<b>Director</b>	<b>Kristjan Oddson (Jan-dec)</b>
	<b>Kristjan Sturluson (dec- )</b>
<b>Chairperson</b>	<b>Jakob S. Jóhannsson</b>

### **The Icelandic Cancer Society's operation**

The operation of the Icelandic Cancer Society (ICS) was efficient in 2016 as usual as both conventional projects were attended to and new ones implemented or prepared. Difficulties in hiring personnel for certain operational units marked the year, and resulted in their operation and arrangement being revised.

### **Income and costs**

The Icelandic Cancer Society's total income in 2016 was 8.729.464 euros. Gifts accounted for 747.348 euros, legacies for 337.419 euros, subsidies for 3.337.870 euros and others accounted for 4.306.827 euros.

Total operating costs (staff included) were 8.115.016 euros. In 2016, the Icelandic Cancer Society distributed costs on the following areas: Research: 408.461 euros, Prevention: 622.495 euros, cancer/patients care: 4.148.234 euros and on other activities: 2.935.827 euros.

### **Financial affairs**

In October, a long dispute between the ICS and the State regarding the Icelandic Cancer Society's pension obligations was solved. The final solution was that the State took over 85% of the obligations and the ICS 15%. The same solution was reached for the member societies of ICS which had pension obligations. This means a whole new situation for the ICS, as opportunities for new and expanded projects have been created with the financial resources that had previously been put aside due to these pension obligations.

Fundraising for the Cancer Society was successful in the year 2016. Official parties, companies and individuals diligently support the ICS with financial campaigns and collaboration projects. Financial contributions are mainly made during fund raising efforts, but also throughout the year. Furthermore, heredity donations and legacies were prominent in 2016, which is a gesture of special affection for the society. The Cancer Society's well-wishers, who are already around 15.000, support the operation on monthly bases and thus play an important part in securing the stability of the operation.

Despite these positive results in financial affairs uncertainty has prevailed regarding the future arrangement of certain sections of the Cancer Society's operations, especially the screening programs.

### **The screening clinic and cancer screening**

At New Year 2016 there appeared not to be enough personnel to read and interpret x-rays for breast cancer's screening. A temporary solution was found by making an agreement with a company that undertook this task from the beginning of the year, but a more permanent and sustainable solution needed to be found. Concurrently, the Ministry of Welfare has been considering revising organizational structure for mass screening for the country.

The Cancer Society's point of view regarding possible changes is that it should be of highest importance that the screening operation is in secure hands.

According to an agreement made in 2015, clinical breast screening was from New Year the responsibility of specialized professionals at Landspítalinn (University Hospital of Iceland). The screening operation is still located at the Cancer Society's premises although personnel come mainly from Landspítalinn.

The Cancer Society has for a long time advocated screening for colorectal cancer. According to an agreement with the Ministry of Welfare, the Cancer Society undertook to prepare this screening. The next steps should be taken by the Ministry of Welfare and will rely on the State Budget.

### **Communication with general public and trust**

According to a recent survey by a PR company where inquiry was made about trust, the Icelandic Cancer Society scored second highest of societies that work for the good of the general community. Cancer preventive measures and cancer patient support is among the three issues that people are most interested in supporting. Along with excellent personnel the wealth of the Icelandic Cancer Society consists of the trust and good will that the society enjoys. Our personnel accept this responsibility and emphasize a professional and trustworthy work. A new website of the Cancer Society was opened 4<sup>th</sup> of February 2016 and, all the content of the old website was revised simultaneously and updated. The new website is both more accessible and user-friendly than the old one, and usable both for smartphones and tablets.

### **The Science Fund**

The Cancer Society's Science Fund was formally founded in December 2015 with just over 250 million Icelandic kronas initial capital. In the year 2016 fully forming the regulations regarding appropriations and preparing allocations was completed. The Fund's board can allocate up to 10% of the Fund's capital each year to research grants as well as its revenue from the last working year. This is one of the biggest projects that the Icelandic Cancer Society has embarked upon during the recent years and it is anticipated that the Fund's grants will revive cancer research in this country.

### **The Counselling Service**

The Counselling Service increased their operation in phone counselling and strengthened their collaboration with service offices in the country. Revision is needed regarding management of the apartments owned by the society due to the appearance of the new patient hotel of Landspítalinn.

### **The Icelandic Cancer Plan**

The Cancer Plan is a project that has taken far too long to complete, and Iceland is in fact the only Nordic country that does not have such a plan. A counselling group delivered a detailed report in 2015, which has since been under discussion in the Ministry of Welfare.

### **Management and changes**

There have been significant changes in the leadership within the Cancer Society. In the beginning of the year Kristján Oddsson was appointed director and he held that position until 1<sup>st</sup> of December 2016 when Kristján Sturluson succeeded him. In an annual meeting in May 2016, Sigrún Gunnarsdóttir succeeded Jakob Jóhannsson whose chairmanship had come to an end.

### **Member organizations**

The member organizations of the Icelandic Cancer Society are the most important link in the operation. It is theirs to shape the Cancer Society's operation, bring it closer to the public and strengthen it as a unit so the highest success can be achieved in the fight against cancer. Thus, it is important that the work and service of the member organizations will be enhanced for times to come.

*You can read the detailed annual report 2016 from the Icelandic Cancer Society here:*

<https://www.krabb.is/media/frettir/Arsskyrsla-2015-2016-Krabbameinsfelagid-10.pdf>



# The Norwegian Cancer Society

## *Kreftforeningen*

**Secretary General**  
**Chairman of the Board**

**Anna Lise Ryel**  
**Gunn-Elin Aasprong Bjørneboe**

### **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. 192 people are employed by the Norwegian Cancer Society and the number of volunteers is app. 27.500.

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

### **Income and costs**

In 2016, the Norwegian Cancer Society had a total income of 61.696.405 euros. Gifts accounted for 25.098.049 euros, legacies for 15.087.430 euros, subsidies for 12.283.062 euros and others accounted for 9.227.865 euros.

Total operating costs (staff included): 62.680.228 euros.

The Norwegian Cancer Society distributed costs on the following target areas in 2016:  
Research: 27.830.890 euros, prevention: 2.047.241 euros, cancer patients care: 15.855.726 euros and on other activities: 16.946.370 euros.

### **Main fields of activity**

#### **2016 – A Good Year for the Cancer Cause**

The Norwegian Cancer Society achieved success in important areas, such as ad-free cigarette and snuff packaging, bowel cancer screening and HPV “catch-up” vaccines. Incurable cancer and hereditary cancer are now on the agenda. We have also had a central role in the debate and discussions regarding new medicines, the healthcare industry, and new technology.

### **Healthcare industry and seed money**

In order to provide patients with quick access to new treatment and medicines, we have urged national authorities to take advantage of its unique potential to grow the healthcare industry. In 2016, we invested in two new technology companies that can potentially offer improved care and treatment for cancer patients.

### **Research**

The Norwegian Cancer Society awarded a total of 240 million NOK in grants for various projects at Norwegian research institutions in 2016. A total of NOK 180 million in grants were allocated through the Open Call in October. In 2016, we made some changes in the model and organisation of research fund allocations. The reason for these changes was to manage potential conflicts of interest and to increase user involvement in the assessment of research proposals. As part of our commitment to facilitate more clinical cancer research, a total of 15 million NOK was awarded to release clinicians from their positions at five of the country's university hospitals so that they could perform research.

### **Priorities and expensive medicines**

In 2016, there was much debate on the expense and access to new medicines in the field of cancer, and we submitted comments on the white papers on priority setting in the Norwegian health care sector and on medicinal products respectively.

### **Screening – significant milestones for bowel cancer and cervical cancer**

For years, we have been advocating for a national program for bowel cancer screening. It was a great victory when the National Council for Priority Setting in Health Care, in 2016, recommended the implementation of bowel cancer screening as a national service.

### **Volunteer activities**

Volunteers are becoming more and more involved in our activities. In 2016, 27,500 volunteered their time. In 2016, the role of group leader was introduced, which means that volunteers can lead other volunteers.

### **Income and use of funds**

Bequests were one of the largest sources of income in 2016, in the amount of NOK 137.3 million. We had more than 31,000 regular donors who granted us NOK 36.5 million. We received NOK 69 million from the Norwegian National Lottery in 2016. There may be major changes in the allocation of lottery funds after 2018, which may have significant financial consequences for the Norwegian Cancer Society. The total income of EUR 61,7 million for the year consisted of gifts (41%), bequests (24%), subsidies (20%) and other income (15%).

Fundraising percentage was at 80.9 in 2016, increasing from 79.6 in 2015. From 2001–2016, the average annual return on the Norwegian Cancer Society's externally managed funds was 5.5 %. The Norwegian Cancer Society administrates and/or participates in 17 foundations that promote the cancer cause.

### **Knowledge Centre for Research, Technology and Innovation**

The purpose of the Centre is to generate dialogue and interest, offer experiences and engage people, as well as to promote innovation and value creation for health and technology. The Centre will be open to the public, and will be a venue for meetings and events. Construction began in autumn 2016, and the Centre is scheduled to open in September 2017.

### **The Cancer helpline and social media**

The Cancer helpline received nearly 14,000 inquiries in 2016. We have approx. one million visitors to the website, kreftforeningen.no, and 250,000 followers on Facebook.

### **Highlights from 2016:**

#### **Firefighters against cancer**

During Arendal Week, we launched the campaign #brennsikkert (“sure fire”), in cooperation with Firefighters Against Cancer, in the hope that municipalities will ensure that all firefighters have the appropriate equipment and will protect themselves to limit the risk of cancer.

#### **Ad-free tobacco packaging**

On 9 December, the Norwegian Parliament made the decision to impose ad-free tobacco packaging. Yet another milestone in our tobacco prevention efforts.

#### **“My treatment choices”**

In November, the shared decision-making tool “My treatment choices”, (Mine behandlingsvalg) was introduced on the helsenorge.no website. The tool is designed to help patients make informed choices together with their clinicians.

#### **Prostate cancer campaign**

Many celebrities stepped up to raise money for the cancer cause during the November Men and Cancer campaign.

#### **King Olav V’s prize for cancer research 2016**

We hosted the event when Professor Kjetil Taskén, from the University of Oslo, was awarded the 2016 King Olav V’s Prize for Cancer Research.

#### **“Combat Cancer” campaign (Krafttak mot kreft)**

A total of NOK 37.5 million was raised by organisations, businesses and 20,000 graduating upper secondary students.

#### **The Norwegian Cancer Society’s 2016 Honorary Award**

Thea Steen received the prize for her efforts in motivating more women to get checked for cervical cancer.

#### **”I’ll shovel snow. You make the coffee”**

We launched the website “Lameghjelpe.no” (“Letmehelp.no”). By using physical or electronic gift cards, friends and neighbours can offer assistance with housework, trying out wigs, cinema visits, and other types of assistance and experiences for cancer patients.

*You can read the detailed annual report 2016 from the Norwegian Cancer Society here:*

[https://kreftforeningen.no/contentassets/4ada8b9004c74d07aa4a65b92213f441/kreftforeningen\\_arsrapport\\_2016\\_enkeltsider.pdf](https://kreftforeningen.no/contentassets/4ada8b9004c74d07aa4a65b92213f441/kreftforeningen_arsrapport_2016_enkeltsider.pdf)

# The Swedish Cancer Society

## *Cancerfonden*

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

**Ulrika Årehed Kågstrøm**  
**Wanja Lundby-Wedin**

### **Structure**

The Swedish Cancer Society is an independent non-profit organisation with no state funding. The Swedish Cancer Society is therefore entirely dependent on legacies and donations from private individuals and corporations. Our vision is to beat cancer and the overall aim is to reduce cancer rates and improve survival rates. The Swedish Cancer Society's main task is to fund cancer research. As one of the largest financiers of cancer research in Sweden, the Swedish Cancer Society essentially acts as a national research council.

Thanks to the organization's extensive knowledge about cancer, the Swedish Cancer Society is also active in areas such as advocacy, public opinion and spreading knowledge about cancer, as well as results of cancer research.

The Swedish Cancer Society was founded in 1951 by the gentlemen's outfitter Morri Nidén and housewife Ebba Andersson. They had one thing in common – both had had cancer and survived. During their illness, they met some cancer researchers and discovered that many more patients would survive if more research was conducted. The solution was an organisation that could channel funds to the researchers. And that's why they founded the Swedish Cancer Society, or rather "The National Society for the Fighting of Cancer Diseases", as it was called at the time. The drive and commitment of Ebba and Morris has been an inspiration to the Swedish Cancer Society's operations ever since.

### **Income and costs**

In 2016, the Swedish Cancer Society's income was 72.300.000 euros. Legacies for 24.000.000 euros, memorial donations 8.300.000 euros and other gifts and revenue 40.000.000 euros.

Total operating costs, staff included, were 64.500.000 euros.

The Swedish Cancer Society distributed funds to the following target areas: 47.900.000 euros to research, 6.400.000 euros to knowledge spreading & advocacy, 9.500.000 to fundraising costs (incl. Rikslotteriet lottery) and 700.000 euros to other areas.

### **Strategic focus and long-term goals**

To beat cancer there are many challenges, but they are not impossible. Rapid progress is being made in research and care. The Swedish Cancer Society wants these advances to reach everyone affected by cancer. This is why we are working to ensure that Sweden's **cancer care is as good, effective and equal** as possible.

### **Main fields of activity**

#### **Financing research**

The Swedish Cancer Society's core activity is financing research. The crucial aspects to consider when awarding grants are each project's originality, anticipated news value and feasibility, and its link to cancer. The process of selecting the very best research projects follows established procedures and is closely regulated. In May each year researchers submit applications describing the aims and expected results of their projects, along with a cost calculation. Applications are forwarded to eight different prioritization committees for evaluation. The various committees' proposals are assessed in October, and in November the Research Commission makes a decision regarding which projects will be funded. The committees and the Commission jointly include some 60 experts in various cancer-related areas.

#### **Opinion-leading and the spreading of knowledge**

As one of Sweden's largest organizations in the field of cancer, it is vital to actively participate in the general debate about the disease. In 2001 The Swedish Cancer Society started promoting the idea of a collective strategy for fighting cancer in Sweden – expressed by the need for a National Cancer Plan.

The aim of the annual Swedish Cancer Society Report is to strengthen opinion-leading efforts, and to contribute with the Society's knowledge and experience in order to highlight problems in the area of cancer. We are happy to verify that The National Board of Health and Welfare (Socialstyrelsen) has now started to implement the plan.

Another task that lies within the frame of the Swedish Cancer Society's opinion-leading efforts is cancer prevention. Efforts in this area are focused on the dangers associated with use of tobacco and excessive exposure to the sun.

#### **Fundraising**

As a non-profit organization, the Swedish Cancer Society receives no government funding, and is therefore entirely dependent on private donations. The main bulk of donations comes from private individuals and companies although legacies represent a significant proportion. The donors can choose between a dozen different ways to support the Swedish Cancer Society. Fundraising activities are constantly developing in order to improve effectiveness. The best known and most widely spread fundraising activity is the Pink Ribbon campaign for breast cancer. Companies, organizations and private individuals all over Sweden take part in all kinds of different fundraising activities in the campaign month, which is October. The aim of the campaign is to finance research, increase awareness of breast cancer and arouse public opinion within the breast cancer area.

The Swedish Cancer Society also aims to increase knowledge about the non-profit sector in general. Non-profit organizations operate under different conditions to public services and the private sector, and for as long as knowledge of their situation remains poor, non-profit bodies are obliged to adapt to the rules of play of other sectors.

**Member of the Swedish Fundraising Council**

Along with 125 other fundraising organizations, the Swedish Cancer Society is a member of the Swedish Fundraising Council. The mission of the Swedish Fundraising Council is to promote ethical and professional fundraising and improve the conditions for fundraising through political lobbying and negotiating with commercial suppliers. Ethical questions related to fundraising are very important and the Swedish Fundraising Council has worked out standards and a code of conduct for its members. Since 2003, the Swedish Cancer Society has been certified in accordance with ISO 9001:2000, an international quality code and is inspected in accordance with this international standard each year.

*You can read the detailed annual report 2016 from the Swedish Cancer Society here:*  
[Cancerfondens årsberättelse 2016](#)



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