

ANNUAL REPORT 2003

NORDIC CANCER UNION



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NORDIC CANCER UNION

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REPORT

ANNUAL REPORT 2003 FOR THE NORDIC CANCER UNION

■ by Harri Vertio, Secretary General of the Cancer Society of Finland

4 The Nordic Cancer Union (NCU) was founded in 1949. The birth of the Nordic Cancer Control Plan in 1987 transferred the Nordic cancer leagues to an active era of collaboration. As a result of a lobbying activity and inspired by the European Union "Europe against cancer"-programme, the Nordic Council of Ministers appointed a planning group to give suggestions for a Nordic Cancer Control Plan. This Plan (Handlingsplan mot Kraeft) was published in 1989.

From January 2003, the Cancer Society of Finland took over the chairmanship, the secretariat for the general business of the Nordic Cancer Union, and the secretariat for the Research Committee. Until the end of 2002 the Danish Cancer Society had been taking care of the chairmanship and the secretariat for the general business of the Union and the Swedish Cancer Society managed the secretariat for the Research Committee.

The Nordic Cancer Union today

The Nordic Cancer Union is directed by a Board consisting of the chairmen and secretaries general of the five cancer leagues. The Faroe Islands, Greenland and Åland have an observer status in the NCU Board. The Chairman of the Faroe Islands Cancer Society attends the meetings of the secretaries general. The Board meets once a year, normally in connection with a scientific symposium. The chairmanship rotates by a three year period. The secretaries general meet 3-4 times a year. Chiefs of information, economics and fund raising meet each other, so do the experts of



patient support issues. The Nordic Scientific Board consists of one representative from every national scientific board. The scientific secretariat stays in one country three consecutive years.

Costs

The Nordic Cancer Union uses about EUR 1.2 million per year for joint programs. At year 2003 Denmark paid 23.1%, Finland 7.6 %, Iceland 1.0 %, Norway 19.8 % and Sweden 48.5 % of the total.

Current programs

Current programs include public information, patient support and Nordic cancer research. A special research fund was started in 1989 to increase support for cancer research projects in the Nordic countries, in both planning and implementation phases. In all, the population of the Nordic countries is about 22 million, which is a good base for cancer epidemiology. Also, clinical studies especially in rare cancers benefit from a joint funding system. The fund is run by a special secretariat and the steering committee comprises one representative from every scientific committee of the national cancer leagues.

In recent years the amount of funds allocated from this fund has been approximately EUR 0.7 million per year. The following criteria must be met:

- The project must be relevant to cancer
- The project must be a joint project involving at least two Nordic countries
- Nordic synergy is essential
- The project must lead to new, relevant findings

Evaluation of the research fund has shown that it stimulates Nordic cancer research and creates synergy. **5**

NCU and ANCR

The cancer registries continue their very close cooperation via the Association of the Nordic Cancer registries (ANCR). The NCU continues to support joint research programs.

All this cooperation has led to fruitful advocacy and lobbying in the EU and in international cancer organisations. Joint programs have increased knowledge on Nordic cancer problems and ways to solve them. The networking has stimulated the individual organisations. Joint programs have increased knowledge on Nordic cancer problems and ways to solve them. The networking has stimulated the individual cancer societies and eventually made them stronger. These years have also shown which joint actions are not cost-effective.

Nordic Action Plan

Some political initiatives also took place. One of them was the initiative to the Nordic Council concerning Nordic Action Plan against the harmful Effects of Tobacco. That plan was never approved for action. The NCU also lobbied actively in the issue of European Union Directive which prohibits tobacco advertising by the year 2006. The Directive was passed in May 1998, annulled later and passed in a new form in 2002.

During several years, the NCU gave financial support to Acta Oncologica, a scientific periodical for the five Nordic societies of oncology.

6 Meeting activities

Being responsible for coordinating the cooperation, the Nordic cancer societies' secretaries general held three meetings in 2003. In connection with the meeting in May in Finland a joint NCU-ANCR joint workshop meeting was held between the secretaries general and the Heads of the Registers in the Nordic countries, during which exchange of experience and options for future collaboration were discussed.

Budget procedure

The Board has decided the following budget procedure:

- at the first meeting of each year, the secretaries general should approve a draft budget framework for the research fund and the other activities
- the framework should be presented to the NCU Board for adoption, and
- the framework for other activities be filled in on the basis of applications from the cancer societies at a meeting of the secretaries general in the autumn.

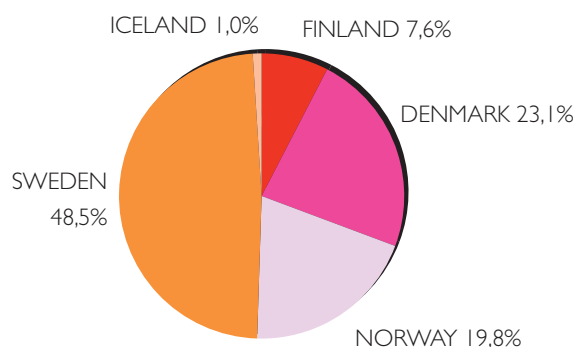
Financing

The Nordic Cancer Union's accounting year coincides with the calendar year. Cost allocation percentages were fixed for distribution of costs between the member countries.

The individual member country's share of the costs is calculated on the basis of the individual societies' income minus any government grants and fundraising costs.

In 2003, the Nordic Cancer Union's budget was EUR 1.200.000; i.e. EUR 700.000 for the research fund and EUR 500.000 for other activities such as patient support and activities within the fields of prevention.

NCU Member Countries' share of the costs in 2003



RESEARCH

REPORT FROM THE NCU RESEARCH COMMITTEE

■ by Tuomo Timonen, Docent, Chairman of the Scientific Committee of NCU

The committee had received 18 applications for evaluation. EUR 700 000 were available for the funding of selected projects.

The chairman of the NCU Research Committee for 2003, Tuomo Timonen, summarized the decisions by the NCU Board 2003, concerning the policy of NCU in the supporting of Nordic cancer research and the volume of financial support suggested for the coming years. The Board had decided that the prioritized areas of research should be clinical trials and epidemiological studies utilizing Nordic cancer registries. In addition, support should be allocated to Nordic umbrella groups to stimulate the planning of such studies. Scientific excellence and a Nordic synergy should be the foremost criteria in the selection of fundable applications.

The Research Committee decided to evaluate the applications of 2003 with the new directions of the NCU board as leading principles. It therefore selected projects only within the prioritized areas and approved only of 1-year project support. In total, 9 proposals were accepted.

The selection procedure, led by the meeting chairman Øystein Bruserud, followed the principles worked out by the Research Committee during the last few years, i.e. the members of the Committee had processed the NCU applications in their respective national review committees. In this way the NCU review process was guaranteed to approve only of projects that had a scientific quality comparable to that of projects approved of in the selection process of research projects at the national level. In the Committee discussions the consensus criteria, i.e. scientific competence of the

research groups, the degree of Nordic synergy and the scientific quality of the projects, were the basic corner stones of the evaluation.

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Following these criteria 9 of the 18 projects were approved of. Of these projects two represented clinical trials, two studies on the genetic predisposition to cancer; two were on epidemiology, one was a quality of life study and one dealt with the clonal heterogeneity of acute lymphoblastic leukemia.

Discussion about the future of the NCU support to cancer research

The Committee discussed the future NCU funding policy. It was unanimously concluded that the support by NCU to Nordic cancer research is of great importance as a means to stimulate unique Nordic research.

The budget

The Committee agreed to convey to the board, through their Chairman, that the NCU research budget is a problem. The present level of support is so low that the administrative effort involved in the selection of applications, and its cost, is too high to be justifiable. It is also imperative that support can be given to a project over a period of 3-5 years. However, it was judged difficult in the present situation of economical constraints in most of the Nordic countries to allocate more money to NCU. It is therefore necessary to give money only to very few projects but at a higher grant level. Therefore, the present new practice should be continued and the Committee suggests that also next year 2-3 projects become funded at

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- 8 the level of EUR 180 000. The rest of the NCU research money should be allocated to support the planning groups which are vital for the continued collaboration in the Nordic countries. "Nordic networking" should be the axis around which the collaborative cancer research should revolve.

The secretariat

If, on the other hand, the budget will be increased, the Research Committee suggests as the last year that the review process should be improved. NCU Research Secretariat should be placed permanently in one of the countries. This Secretariat should improve and modernize (e.g. internet applications) the process of handling and reviewing the applications and ensure that the results are properly followed up and the economy involved is properly documented. At the moment the handling of the whole administrative process of the NCU research support is inferior to that of the national research committees.

RESEARCH

RESEARCH GRANTS AWARDED BY THE NCU IN 2003

Main applicant	Title of project	Amount EURO	9
Aaltonen, Lauri	Genomic variation as a predictor of colorectal cancer risk in Nordic countries, studies of inherited predisposition and molecular mechanisms of tumor formation	180 000	
Alvegård, Thor	Scandinavian Sarcoma Group (SSG). Centralized registration - a SGS musculoskeletal oncology research and multi-disciplinary approach	20 000	
Feychting, Maria	Genes, environment, and brain tumor risk	180 000	
Geisler, Christian	Nordic Lymphoma Group: A Nordic collaboration to combat malignant lymphoma	35 000	
Glimelius, Bengt	Colorectal cancer - predictive and clinical studies	30 000	
Hjorth, Martin	Nordic Myeloma Study Group (NMSG). Organisation, clinical trials and basic research in multiple myeloma	20 000	
Lewensohn, Rolf	Stereotactic radiotherapy of early stage lung cancer	180 000	
Lönnholm, Gudmar	In vitro cellular drug resistance in childhood acute lymphoblastic leukemia: a Nordic multicenter study	30 000	
Wille-Jørgensen, Peer	Intensive follow-up programme versus less intensive follow-up programme for patients having radical surgery for colorectal cancer. A randomised multicenter study – COLOFOL	25 000	

RESEARCH

CANCER INCIDENCE AMONG 10,211 AIRLINE PILOTS: A NORDIC STUDY

Eero Pukkala¹, Rafael Aspholm², Anssi Auvinen³, Harald Eliasch⁴, Maryanne Gundestrup⁵, Tor Haldorsen⁶, Niklas Hammar⁷, Jón Hrafnkelsson⁸, Pentti Kyyrönen¹, Anette Linnarsjö⁷, Vilhjálmur Rafnsson⁹, Hans Storm¹⁰, Ulf Tveten¹¹

Source: *Aviation, Space, and Environmental Medicine Journal*, Vol 74, No 7, July 2003. Permission to reprint by the Aerospace Medical Association.

10 Abstract

Objective

- To assess the incidence of cancer among male airline pilots in the Nordic countries, with special reference to risk related to cosmic radiation.

Design

- Retrospective cohort study, with follow up of cancer incidence through the national cancer registries.

Setting

- Denmark, Finland, Iceland, Norway, and Sweden.

Participants

- 10,211 airline pilots, with an average follow up of 17 years.

Main outcome measures

- Standardised incidence ratios, with expected numbers based on national cancer incidence rates; dose-response analysis using Poisson regression.

Results

- 466 cases of cancer were diagnosed compared with 456 expected. The only significantly increased standardised incidence ratios were for skin cancer: melanoma 2.3 (95% CI 1.7-3.0), squamous cell cancer 2.1 (1.4-3.1), and basal cell carcinoma 2.5 (1.9-3.2). The relative risk of skin cancers increased with the estimated radiation dose. The relative risk of prostate

cancer increased with increasing number of flight hours in long-distance aircraft.

Conclusions

- This large study, based on reliable cancer incidence data, showed an increased incidence of skin cancer. It does not indicate a marked increase in cancer risk attributable to cosmic radiation although some influence of cosmic radiation on skin cancer cannot be entirely excluded.

Introduction

Airline pilots are occupationally exposed to ionizing radiation with doses 2-6 mSv per year. The average annual dose from natural and medical sources received by the general population is about 2 mSv. Cosmic radiation in the common cruising altitudes consists mainly of gamma and neutron radiation, with some heavy nuclei. In 1990, the International Commission on Radiological Protection recommended that in-flight natural background radiation exposure to jet aircrew should be regarded as an occupational exposure. Besides cosmic radiation, flight personnel may also be exposed to electromagnetic fields (EMF) from cockpit instruments, jet fuel and other volatile substances emanating from aircraft construction materials, varying, e.g., by type of aircraft and time period.

It is important, both to the flight personnel and to frequent flyers, to determine if their risk of

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cancer is elevated due to ionizing radiation and whether current occupational standards provide sufficient protection. The aim of this study was to describe the cancer incidence among commercial airline pilots from all five Nordic countries.

Material and methods

National cohorts of airline pilots were identified from various registers in the Nordic countries. The cohorts were linked to the national population registers, and the correct personal identifier (PI) and the possible dates of emigration, immigration or death were obtained for every cohort member. Follow-up for incident cancer cases was done through record linkage with the national country-wide cancer registries existing in all Nordic countries.

Relative risk estimates were calculated by the number of block hours in different types of flights, which were collected mainly on annual basis from the seniority lists and other documents on flight histories. The aircraft was classified by an expert panel into low-altitude, intermediate distance and long distance categories, similarly in all countries.

Results

There were 10,051 men and 160 women under follow-up in the cohort. The mean length of follow-up was 17 years. Almost 30% of the person-years were in the follow-up category of at least 20 years since the time of first employment (Table 1). The cohort was rather young: only 23% of the person-years were in age categories above 50 years.

Table 1.
Numbers and percentages of person-years at risk among male airline pilots, by study variables.

Variable	Category	Person-years	%
Country	Denmark	65,086	37
	Finland	14,600	8
	Iceland	2,520	1
	Norway	65,837	37
	Sweden	29,200	16
	Whole Nordic	177,243	100
Age (years)	< 30	32,897	19
	30-39	57,297	32
	40-49	45,771	26
	50-59	26,886	15
	60-69	11,244	6
	≥ 70	3,151	2
Time since first exposure (years)	<10	76,176	43
	10-19.9	49,763	28
	≥ 20	51,304	29
Block hours at any air craft^a	1-999	22,423	12
	1,000-4,999	51,487	29
	5,000-9,999	39,244	22
	≥ 10,000	40,035	23
Block hours, low-altitude^a	1-4,999	78,934	44
	5,000-9,999	28,547	16
	≥ 10,000	14,603	8
Block hours, long-haul^a	1-4,999	33,848	19
	5,000-9,999	13,673	8
	≥ 10,000	10,922	6
Estimated dose (μSv)^a	1-2,999	82,249	46
	3,000-9,999	26,089	15
	10,000-19,999	24,201	14
	≥ 20,000	20,004	11

^aDo not add up to 177,243 person-years (or 100%), because the category no/unknown exposure is excluded.

During the follow-up, 466 cases of cancer were diagnosed in males; the expected number was 456. In females, only two cancers (one in the breast and one in the corpus uteri) were observed vs. 1.8 expected. Therefore, all results in the following only concern male pilots.

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The only statistically significantly increased SIRs were seen in various categories of skin cancer. Skin melanoma of the head and neck showed an SIR of 2.49, trunk 2.33 and limbs 2.29. The SIR for non-melanoma skin cancer (excluding basal cell carcinoma) was 2.08. Data for basal cell carcinoma were only available from Denmark and Finland; they show an SIR estimate of 2.46. The RR for skin melanoma increased with cumulative dose (Table 2).

The RR of prostate cancer in ages ≤ 60 increased with the number of block-hours in long-haul aircraft: pilots with $\geq 10,000$ block hours had 8 cases, RR 3.88, 95% CI 1.26-11.9 in comparison with category of < 5000 block hours (p trend 0.01).

Discussion

A meta-analysis of earlier studies showed excess mortality from skin melanoma (SMR 2.0, 95% CI 1.0 - 3.8) and brain cancer (1.5, 0.9 - 2.2), and elevated incidence of prostate cancer (SIR 1.7, 95% CI 1.2 - 2.3) and brain cancer (1.7, 0.9 - 3.3).

The present joint Nordic study only confirmed the findings concerning elevated risk of skin cancers. Melatonin may have a protective effect against cancer development, especially in hormone-dependent tumours, and disruptions in sleep-waking cycles may increase cancer risk by suppressing melatonin secretion. According to that theory flight personnel flying over numerous time zones might have an excess risk. We saw a risk increase with increasing number of long-haul hours and cannot fully exclude the possibility that jet lag would increase the risk of hormone-related cancers.

The large size of the joint Nordic cohort reduces the possibility of chance findings, and having access to carefully registered incidence data helps to avoid artefacts possibly included in the routine mortality statistics.

Table 2. Observed numbers of selected cancers (Obs) among male airline pilots in the Nordic countries, and relative risk estimates (RR) derived from Poisson regression model, with 95% confidence intervals (CI), by estimated cumulative dose. Adjusted for age and calendar period.

Primary site	All sites ^a			Skin melanoma			Other skin ^a			BCC ^b			Non-CLL ^c		
	Obs	RR	95% CI	Obs	RR	95% CI	Obs	RR	95% CI	Obs	RR	95% CI	Obs	RR	95% CI
Cumulative dose (μ Sv)															
1-2,999	149	1.00	ref.	14	1.00	ref.	7	1.00	ref.	7	1.00	ref.	3	1.00	ref.
3,000-9,999	52	1.12	0.81-1.53	9	2.10	0.91-4.87	1	0.52	0.06-4.26	6	1.83	0.70-4.79	2	1.90	0.32-11.5
10,000-19,999	93	1.19	0.92-1.54	13	2.20	1.03-4.72	6	1.50	0.50-4.48	8	1.42	0.60-3.41	2	1.42	0.23-8.70
$\geq 20,000$	137	1.19	0.93-1.51	17	2.78	1.30-5.93	12	1.92	0.74-4.98	32	1.86	0.98-3.54	3	1.78	0.32-10.0

^a Excludes basal cell carcinoma, and in Denmark all non-melanoma skin cancers diagnosed before 1979.

^b Basal cell carcinoma of the skin; only Denmark (1979-1996) and Finland (1953-1997).

^c Leukemia, excluding chronic lymphatic leukemia.

Follow-up for deaths and emigration is complete in the Nordic countries, and therefore the person-year calculations are reliable.

There are few areas outside the Nordic countries with a history of several decades of population-based registration of cancer. Because our cohort included most of the cockpit crew ever certified in these countries, this study can be considered as having the maximal potential in the whole world to study cancer incidence among pilots.

It is virtually impossible that our observations concerning increased risk of skin melanoma and squamous cell cancer of the skin could be due to chance. Besides skin cancers, Nordic male pilots seem to have a cancer pattern typical to males of high socio-economic position in the Nordic countries. Data from the other Nordic countries did not confirm the previous Danish suggestion of acute myeloid lymphoma being related to radiation dose among pilots.

Unlike the earlier studies, our study was able to compare cancer risk by work history, levels of estimated exposure to ionizing radiation, and take into account cancer characteristics (for example, subtypes of leukemia, and tumor latency.) The present study calls for a need of detailed studies focusing on possible work-related factors involved in the evidently increased skin cancer risk and the suggestive dose-response patterns in prostate cancer.

PATIENT SUPPORT

REPORT FROM THE NCU PATIENT SUPPORT GROUP

■ by Anne Nissen, Chair of the NCU Patient Support Group

14 In 2003 the patient support

area has received support for projects concerning:

- Conference and video about cancer and sexuality 2003/04
- Cancer in Working life - Factors affecting cancer patients' returning to work, their work ability and their work satisfaction
- Men and cancer – psychosocial aspects
- Rehabilitation

The projects concern areas in which there is a need in the Nordic countries for focusing on problems and submit proposals for activities and recommendations with a view to improving the total patient course for cancer patients and their relatives.

The choice of effort areas made by the NCU patient support group is characterized by the fact that the projects must be

- Relevant, so that the results may be of future use to patients and/or relatives
- innovative, must create new knowledge
- of a high quality, original and topical
- performed by professionally competent persons in an environment enabling their implementation
- ethical and morally justifiable

The NCU patient support group has held two meetings in 2003, in Denmark and in Iceland, respectively.

Cancer and Sexuality

The NCU patient support group finds that there is a need for focusing on the theme "Cancer and Sexuality" in the Nordic countries. Discussing how cancer and cancer treatment affects sexuality is of growing importance.

As the number of people with cancer increases and cancer patients live longer, more patients ask questions about how their sexual health will be influenced. Sexuality in general in relation to quality of life has undergone rapid change during recent years. However, there is at present little documentation of the effect of cancer and cancer treatment on quality of life in relation to sexuality.

There is a need for throwing light on the experiences, reactions, thoughts, and feelings, which occur among younger and older adults with cancer and their partners in connection with their identity and sexuality. This will help breaking down taboo subjects and demystifying having cancer.

Although health professionals are today more aware of the importance of a holistic approach to cancer treatment and care, talking about sex is often still taboo in the Nordic countries. Evidence based practice shows that health professionals, patients and relatives at times find communication connected to sex challenging. Dialogue often may be hampered by a lack of vocabulary, some times mixed with feelings of guilt and shame, isolation and psychological suffering.

Holistic treatment and care for cancer patients and their relatives includes awareness of the meaning of sexuality, and reflection over the effect of treatment on body image, social

relationships, psychological and existential issues for both patients and their relatives. Approaches to both cancer and sexuality are affected by variations in cultural, religious and lifestyle situations. Cancer patients of all ages and in all stages of illness have a right to meet professionals who are able to support them to express sexual needs and concerns.

An initiative to a conference on the subject has been taken, including production of a documentary film. Both have received support from the NCU in 2003.

Conference

The 1st NCU Conference on Cancer & Sexuality conference will be held in Oslo 20-21 September 2004.

NCU has in 2002 and 2003 granted financial support for the planning and organising of the upcoming Nordic Conference on Cancer & Sexuality in September 2004.

Key-note speakers, and dialogue in parallel work-shops, will highlight cancer patients right to have a sexual life, discuss stumbling blocks in communication between health professionals and cancer patients and relatives, open for dialogue on cancer and sexuality from both female and male perspectives, take up issues related to technical sexual facilitators, illuminate sexuality in a life-long perspective and focus on ethnic issues related to sexuality and cancer.

The conference aims to increase participants' insight into sexology in relation to cancer. It will hopefully provide a meaningful basis for an as yet underdeveloped issue: development of Nordic guidelines for professional practice in relation to sexuality and cancer treatment and care.

The Scientific Committee of the Conference consists of 9 members from all the Nordic countries. The Scientific Committee met three times in 2003 and they have prepared a very comprehensive and varied scientific programme. The local host Norwegian Cancer Society expects that approximately 200 persons will attend the Conference. The official language of the Conference will be English.

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Documentary film

Experiences from other documentary films about difficult and sensitive subjects concerning human problems and relations have shown that a warm and varied documentary film creates dialogues, which in many cases offer problem solutions and move boundaries.

The target group is mainly persons – patients and nearest relations – to whom the problems are close, but also professionals in the health sector; the local cancer centres, staff, and others. The film can be used for educational purposes, conferences, and courses in connection with various educations in the health and social sector, where it will present sound information and introduction to a debate.

The film will be an “idea catalogue” how to approach/solve the many problems in an optimum way. The form of the film is documentary and will be a mix between warm, varied interviews and cuttings from the everyday life of the performers. It is built around 4-5 couples and 1-2 singles, who want to establish or have established a relationship. The age spreading is approximately 25-70 years. It is important that the age spreading is wide because problems and experiences differ during the different phases.

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- 16** The length of the film will be 45 minutes. The film will be available as DVD with a book-let in the Nordic languages. The presentation of the film is planned to take place in connection with the conference in Oslo, September 2004.

Cancer in working life

Although cancer is still and will remain mostly a disease of the elderly population, there are many cancer patients who have many years until retirement. The prognoses are continuously improving in many cancers and thus more and more patients could return to work after treatment and even during it. Cancer patients willing to return or returning to work may face many problems. This project aims to shed light on those problems and also find solutions at least to some of them.

The project "Factors affecting return to work, work ability and work satisfaction among cancer patients – A Nordic questionnaire study" is a continuing of project started in April 2002.

The Nordic project group has held two meetings in 2003, one in March in Helsinki in Finland, and one in November in Copenhagen in Denmark.

The draft questionnaire made in 2002 was revised in January 2003 based on the revisions proposed by the Nordic participants and it was pilot-tested in Finland in February 2003. After the meeting in March the questionnaire was finalised and it was translated into other Nordic languages following the EORTC Quality of Life Group Translation Procedure. In November meeting the experiences of data collection were presented and discussed. The Nordic meetings is arranged to discuss the design issues of the study, follow-up the progress of the study in each country, plan the centralised

data analysis of combined Nordic questionnaire data, discuss the results and prepare a publication based on the combined data.

Cancer rehabilitation in NCU

Introduction

In 2002 it was decided in NCU to establish and support a Nordic project group (two persons per country) with focus on cancer rehabilitation.

Cancer rehabilitation is still in the early learning curve and there is a lack of collected knowledge and documentation of what cancer patients needs in their rehabilitation process. There is not a structured format of transforming knowledge of "who needs what and when" to be implemented generally to all cancer patients.

The idea was to create a network of dedicated persons within cancer rehabilitation in order to create a Nordic definition of rehabilitation and to explore which areas to gain synergy and to define which areas of cooperation would be possible.

Objective

Based upon the first meeting the conclusion was that it does make sense to create this network. All countries can use the support of a Nordic cooperation with the objective to keep cancer rehabilitation on the agenda. "How to maintain the positive development of cancer rehabilitation per country in spite the fact that the countries has different entry's to the area."

Our objective is to create a “booklet / brochure” with the starting point in a Nordic helicopter view of cancer rehabilitation.

The target group is health personal in both primary & secondary, politicians and patient support organisations per country.

The booklet will include recommendations, definitions and examples of rehabilitation programmes.

With the booklet we strive to secure cross-country knowledge sharing, to create a platform of which each country can work onwards on by creating a common understanding of the phenomenon.

Status

We are in the process of collecting all written material which has been created on ad hoc groups cross country. A journalist will support the final writing of the booklet during spring. During the process the group will meet to discuss the contents.

The goal is to present the booklet at an international workshop in Copenhagen August 2004, in which NCU has one workshop day in cancer rehabilitation. Hereafter we will market the booklet individually per country.

INFORMATION AND PREVENTATION

HEALTH EDUCATION AND DOCUMENTATION

■ By Hans H Storm and Satu Lipponen

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information and prevention departments traditionally meet annually to exchange information and ideas. In 2002 it was decided to combine these meetings with ongoing joint activities. In 2003 the information and prevention heads met on a few occasions whereas staff members dealing with activities listed below met on practical details in the joint projects. Part of the health education and documentation is related to the long lasting Nordic collaboration between cancer registries, where most originated from Cancer Societies. Even if now only the Icelandic and the Finnish cancer registry is part of cancer societies, the documentation, education and research is still a fundamental part of the activities of the Nordic Cancer Union. As an ongoing activity, the NCU supports the summer school in cancer epidemiology run by the Association of Nordic Cancer registries, and the NORDCAN software enabling comparisons on cancer incidence and mortality in the Nordic countries. The same collaboration is constantly producing key figures on cancer incidence, mortality, survival and prevalence to be used by the NCU in formulating policies on cancer nationally and on a Nordic level.

In 2003 the European Cancer Code was revised and it is clear that public health can be improved and the cancer burden decreased by actions on tobacco, obesity, physical activity, diet – fruits and vegetables, alcohol, UV-radiation, reduced exposures in the working environment and establishment of screening for cervix, breast and colorectal cancer. Traditionally the NCU members have worked closely together on the tobacco issue.



12th World Conference on Tobacco or Health in Helsinki, 3-8 August, 2003

The Nordic Cancer Union and its information and prevention group collaborated in various levels at the 12th World Conference on Tobacco or Health in Helsinki. Cancer Society of Finland was one of the main organisers. NCU Information group prepared together with the Association of the Nordic Cancer Registries a workshop titled Effective tobacco control policy: Evidence from cancer registries chaired by Timo Hakulinen and co-chaired by Tove Kolset. Speakers of the workshop were Satu Lipponen, Hans Storm, Eero Pukkala,

Joanna Didkowska and Richard Peto. The workshop was held August 6th.

A publication titled Nordic Tobacco Control was published August 4th at the Conference. The publication contained articles from all the Nordic countries and their means and policies to reduce smoking. The booklet was a Nordic collaboration project financed by the Nordic Council. Nordic information network of the cancer societies helped in planning and preparing the booklet.

Norwegian Cancer Society had a round-table meeting about women and tobacco and a NCU planning meeting on ethnic minorities and cancer took also place at the World conference.

Nordic conference on prevention among Ethnic minorities

In 2002 the heads of information and prevention, realised that all countries were missing out on particular groups that were hard to reach and that were more and more prominent users of the health care system. These were ethnic minorities, however so small that it would be difficult to justify major information activities on cancer targeted at these groups in each country. Based on this the idea was conceived to join forces realizing that at least symptoms and signs and to a large extent also the health care in the NCU countries would provide the same services, and that common information material in the ethnic minority languages could be developed. Studies have shown the need for prevention and information among these groups. However they do not know what the health care systems can offer and how to approach the systems. Based on this it was decided to begin the process by having a

Nordic conference on ethnic minorities with the key words – information and communication. The conference planning began in 2003 and the NCU members have discussed the problems in each country related to these minority groups. An internal report was developed specifying the ethnic minorities in each country, their knowledge on cancer, cultural barriers and possible methods that can be used to get in contact with the groups. The conference will take place in Malmö, Sweden under the title “Preventing cancer across culture”. The outcome should be a better foundation for joint information material and methods to approach these minority groups in the future.

Symposium on physical activity and cancer 2004

Physical activity is listed as the third most important measure to prevent cancer in the revised European Cancer Code. Physical activity has also proven very important in secondary prevention and rehabilitation of cancer patients. Although the message seems simple to convey to the public, the modern society will - if following the traits seen in the USA - be one with inactive and obese citizens. The Information heads of the NCU members felt that this prevention arena opened for possibilities of joining forces, both with respect to increased knowledge on the background, and by sharing ideas and testing activities that could be implemented on a broad population scale. A symposium on cancer and physical activity will be arranged as the first step. It will be hosted by the Danish Cancer Society in collaboration with the Nordic Cancer Union. The main theme is behavioural trends in the broad population and the question of reaching the inactive and motivating 1/2 hour of

20 moderate intensity physical activity every day. A few “state of the art” presentations on “Association between cancer and physical activity/overweight from a epidemiological as well as a physiological perspective will be conducted during the symposium. A small session on “Physical activity in cancer treatment and rehabilitation” will also take place during the symposium. Based on the symposium it is envisaged that the NCU members hereafter can target common goals and create a Nordic synergy on specific projects increasing the physical activity of the populations.

Nordcan and cancer surveillance

In 2003 the second update of the NORDCAN software was launched on the NCU website <http://ncu.cancer.dk/ancr> from where users for free can download the software. Also a “manual” explaining the facilities and how to use them is now available. The software is well taken and many users have listed by names to receive messages about updates and errors etc. The software can be used by virtually anybody, and is very popular amongst clinicians and journalists. The update in 2003 meant an expansion of the period where data is available – namely now back to 1970 and up to 1999, all on the level of counties in each of the Nordic countries.

The collaboration behind the software – the Association of Nordic Cancer Registries – also worked during 2003 on new survival estimates and detailed study on possible explanations for survival differences among cancer patients in the Nordic countries. The first publication comparing Denmark and Sweden – South will be published in the spring 2004, the main finding being a better prognosis related to the earlier diagnose in Sweden for

ages 50-79 years. Predictions on cancer into year 2020 was published in 2002 and in 2003 further scientific papers on the methods used.

Nordic summer school in cancer epidemiology

For the 6th time 25 Nordic pre graduate or very young candidates was offered training in cancer epidemiology on a grant from the Nordic Cancer Union. The summer school consists of a 2 weeks basic course, given by the best teachers in the Nordic countries in contact with the Cancer Societies and Cancer Registries, followed by a 2-3 month long practical phase in an epidemiological research institute – such as a cancer registry – on a given project. This year 3 projects concerned prostate cancer. The students present their work at a week-end seminar in January the following year and in 2004 this was hosted by the Finnish Cancer Registry and the Tampere University. The summer school is very successful and many of the registries have got good return on the investment by having attracted young and skilled researchers to their staff. In the long run the investment will be an important public health contribution from the NCU.

MEMBER ORGANISATIONS



Structure of the organisation

The Danish Cancer Society is a voluntary, non-profit national association, with 261 local units and committees. Approx. 1,500 volunteers sit on the boards of the local units. The Danish Cancer Society has approx. 288 000 members.

Income and costs

In 2003 the income was DKK 376 million of which inheritance accounted for DKK 130.3 million, lotteries accounted for DKK 39.7 million, and the annual door-knocking campaign for DKK 25.6 million. In 2003, the Danish Cancer Society distributed costs on the following target areas: Research DKK 177.7 million, patient support DKK 68.9 million, prevention and information DKK 47.8 million, administration DKK 20.1 million.

Main fields of activity 2003

The main activities are within research, patient support and prevention.

Research

The Danish Cancer Society's research pivots on two key areas: biological, experimental research and epidemiological research. In 2003, Danish Cancer Society researchers published more than 108 articles in leading international scientific journals.

Within the research area the establishment of the Danish Centre for Translational Breast Cancer research – DCTB marked an era. The DCTB is a co-operation between a number of Denmark's top researchers and physicians on breast cancer. The participants of the DCTB are convinced that the co-operation will result in a major breakthrough in the treatment of breast cancer.

The epidemiological research focused on a research programme concerning Diet, Cancer and Health, Environment and Cancer, Genetics and Medicine, Psychosocial Cancer Research, Viruses, Hormones and Cancer, and Biostatistics and Data Processing.

In 2003 there has been and still is great focus in Denmark on mobile telephony, transmitter masts, and the risk of damaging effects from these units. The Danish Cancer Society has participated actively in the debate, and the Society's researchers have contributed to illuminating the problem. The Danish Government has now decided to set aside means for further research in this field, especially relating

to children and young people.

Patient support

Within the patient support area there has been increased focus on patient-centred health care. In particular, there seems to be heightened interest in involving the patient's perspective more significantly in health care. The Danish Cancer Society has - together with a number of other organisations - participated in preparation of 20 recommendations on interpersonal relations. With these recommendations, a significant framework has been laid out for the continued development and a strengthening of patient-centred health care within the Danish health service. In addition, there has been focus on gathering patient experiences from the consulting work. Likewise the Danish Cancer Society has placed seriously ill and dying cancer patients on the agenda.

Prevention

In the field of tobacco it is positive that the number of smokers in Denmark is the lowest ever. Among other things this is due to the united European effort against smoking. The effort in the food area continues and is increased during the "6 a day" campaign. This campaign is a cooperation between the health organisations, the trade, and the authorities.

Highlights in 2003

In 2003 a further step towards the implementation of the national cancer control plan was taken – great progress was made, especially concerning the extension of the treatment capacity and thereby a reduction of the waiting times. By now already the national cancer control plan has involved a supply of 1.5 billion Danish crowns to the cancer area as well as an increase of the activities of 75%. The need for treatment and the treatment capacity are close to a balance. However, there are a number of points in the cancer control plan which remain to be implemented, for instance improvements concerning early diagnosis, rehabilitation and palliation. The Danish Cancer Society has contributed and continues to contribute to speed up this development.

In 2003 the Danish Cancer Society celebrated its 75 years anniversary. The anniversary was marked by events and activities throughout the country.

MEMBER ORGANISATIONS



CANCER SOCIETY OF FINLAND
SUOMEN SYÖPÄYHDISTYS

22 Structure

The Cancer Society of Finland, founded in 1936, is one of Finland's largest public health organisations. It is an umbrella organisation for 16 registered member organisations. Twelve of these are regional cancer societies, the remaining four are nation-wide patient organisations.

The funding of the Cancer Society of Finland comes from donations and bequests, special activities for financial support, fees for services of the laboratory- and outpatient clinics, membership fees, and grants from the Finnish Slot Machine Association.

The Finnish Cancer Foundation, the Finnish Cancer Registry and the Finnish Foundation for Cancer Research function in connection with the Cancer Society of Finland.

Main fields of activity

- health promotion
- public information
- patient support and rehabilitation
- cancer screenings
- maintenance of outpatient clinics, cytological and histological laboratories and a few hospices
- advocacy
- fund raising

Highlights of activities in 2003

Health promotion and public information activities continued actively.

A wide variety of psychosocial support services were provided throughout the country. The calling time of the free telephone helpline was lengthened by two hours daily due to an increased demand for the service.

The Finnish Cancer Foundations granted a record amount of 3 million euros for cancer research as in 2002.

Planning of the colorectal cancer screening continued and the screening will start in 2004. The Society paid a lot of attention in maintaining the quality control concerning screening.

The 12th World Conference on Tobacco or Health took place in Helsinki on 3 - 8 August, 2003, with an attendance of 2300 participants from all over the world. Secretary General Liisa Elovainio was the President of the conference. The Organising Committee was represented by the Cancer Society of Finland, National Public Health Institute and the Finnish Centre for Health Promotion. The congress was a great success in all ways.

Liisa Elovainio was the Vice-President of the Association of European Cancer Leagues (ECL) for the period 2001-2003.

The chairmanship, secretariat and research fund of the Nordic Cancer Union are in the Cancer Society of Finland during the years 2003-2005.

The Secretary General Liisa Elovainio retired in November 2003. The new Secretary General Harri Vertio, MD, Ph.D., was appointed from 1st December 2003.

MEMBER ORGANISATIONS



THE ICELANDIC CANCER SOCIETY KRABBAMEINSFÉLAG ÍSLANDS

Structure

The Icelandic Cancer Society is a nation-wide, voluntary organisation with 19 active, regional divisions, and 7 cancer patients' self-help groups, and a membership of around 10,000. At the same time the society, with about 90 employees, can also be regarded as an institution with multiple functions that plays an important role in the Icelandic health service. The society's activities are primarily financed by donations, income from sale of lottery tickets, remembrance cards and logos together with other fundraising activities such as door-to-door collection campaigns. We have introduced various new approaches in financing during the last year. Another source of income is through an agreement between the health authorities and the Cancer Society, which organises a Cancer Detection Clinic and carries out a nation-wide screening programme for cervical cancer (20-69 years) since 1964 and breast cancer (40-69 years) since 1987. Women older than 69 years are welcome but not specially invited. The screening clinic takes part in an international research programme on vaccination against HPV and cervical cancer. The society's total income is EUR 4.430.995.

Apart from **the national screening programme**, the Icelandic Cancer Society is responsible for a variety of functions as e.g. **general information and education about cancer and tobacco prevention**. This has contributed to a continuing reduction in smoking of young people.

The society runs a Molecular and Cell Biology Laboratory with a main emphasis on breast cancer research. The Icelandic Cancer Registry, an extremely valuable population based data bank, is run under the auspices of the society and is busy preparing a celebration of its 50th anniversary in May 2004. The society supports a Home Care Service, providing medical and nursing support for cancer patients in the capital area, who wish to stay at home as long as their condition permits. There continues to be a great demand for the seven flats purchased by the society in partnership with the Icelandic Red Cross and the Organisation for Disabled that are run by

the University Hospital and more are on their way. They are for cancer patients and their families from the countryside who can stay there when they come to the capital for treatment, the reasonable rent being covered by their local chapter.

The society continues to strengthen its support of the member organisations, stimulating formation of new chapters, as well as offering the patients self-help groups a programme of rehabilitation and training for volunteers, connected with our telephone information and support line for cancer patients. A valuable handbook for cancer patients and their families was published during the year by one of the patients groups and can be found here: http://www.kraftur.org/felagid.asp?cat_id=3

The society hosted the annual joint symposium of the Nordic Cancer Registries and Societies in September with the theme: Complementary and alternative medicine. Most of the talks can be found here: <http://www.krabb.is/ncu2003/>

MEMBER ORGANISATIONS



NORWEGIAN CANCER SOCIETY KREFTFORENINGEN

24 Structure of the Organisation

The Norwegian Cancer Society (NCS) is a non-profit nation-wide, voluntary organisation with approximately 150 000 members and permanent donors. NCS does not receive any money from the Norwegian authorities, and is thus totally dependent on the generosity, support and confidence of the general public.

The NCS has during 2003 undergone an extensive reorganising process. The numbers of departments are reduced from 9 to 3. The new organisation is operational as from 1 January 2004.

In 2003 the income was NOK 343 million (EUR 38 million). The main 3 sources of income was membership fees/contributions, inheritance and electronic games. In 2003 Norwegian Cancer Society mainly distributed costs on the following target areas: Cancer Research, patient support and prevention.

Research

The NCS is a major contributor to research in Norway and acts as a driving force for broad based cancer research of high international standard in Norway, to ensure optimum diagnosis and treatment of cancer. Of a total of 460 persons who were on the NCS's monthly payroll in 2003, 274 persons were engaged in research. The research activities are integrated with the research carried out at universities and main hospitals in Norway.

Some of the cancer research projects supported by NCS in 2003:

- Research on molecular cancer genetics
- Project Manager Professor Ragnhild A. Lothe.
- New treatment methods on brain cancer
- Project Manager Professor Rolf Bjerkvig
- Mathematical analyses of cancer patient studies and clinical cancer studies
- Project Manager Professor Odd O. Aalen

Patient support

The NCS continued in 2003 its nation-wide efforts to improve the quality of patient care and support, and achieve a more equal distribution of services for cancer patients and their relatives. The Cancer Helpline Telephone did in 2003 receive approx. 3 200 inquires from cancer patients, relatives and health professionals. The counselling centres all over Norway received many inquires from patients, relatives and health professionals, and the counselling centres also hosted educational courses and meetings for health professionals and students.

The NCS supports financially the 10 cancer patients' associations that are affiliated to the NCS. The associations are national organisations offering members social contact, support and rehabilitation. They also disseminate information, and run visiting services. List of the 10 affiliated organisations:

- The Norwegian Breast Cancer Society
- Norwegian Society for Laryngectomees
- The Norwegian Cancer Society Youth Group
- The Society for the support of Children with Cancer
- The Norwegian Ostomy Association (NORILCO)
- The Norwegian Association for Persons with Transplanted Bone Marrow
- The Gynaecological Cancer Association
- The Norwegian Association Against Tobacco
- Carci-Nor
- The Prostate Cancer Association

Prevention

NCS has in 2003 focused mainly on nutrition, tobacco control activities and preparing a Norwegian version of the European Cancer Codes. NCS has initiated a programme in the junior high school to encourage children to eat more fruit and vegetables. NCS has also initiated projects to reduce smoking at work and to reduce smoking among women.

MEMBER ORGANISATIONS



THE SWEDISH CANCER SOCIETY CANCERFONDEN

Structure

The Swedish Cancer Society is a non-profit organisation whose task is to collect money and distribute it for cancer research, provide information about cancer and give support to activities which in various ways may contribute to improvements in cancer treatment and care.

Founded in 1951, the Swedish Cancer Society has behind it 38 trustees representing practically the whole range of organisations and associations in Sweden.

As a non-profit organisation, the Swedish Cancer Society receives no state aid, but is entirely dependent on donations from the people of Sweden. Via these donations, legacies and campaigns, the Swedish Cancer Society funds 75 percent of all cancer research projects, which compete on a national basis and are prioritised by scientific experts.

Of the society's annual turnover, 70 percent goes directly to research and 30 percent goes to the Swedish Cancer Society's other work, including prevention, information and care development.

Research

2003 saw SEK 299 million granted to 405 research projects and 16 planning groups for coordinating research in 2004. Awarding grants is sensitive work requiring strict principles. The evaluation process takes a total of five months and every application is scrutinised and evaluated in five stages.

The Swedish Cancer Society supports cancer research on a broad front. The vast majority of the funds, around 80 percent, are allocated to projects initiated by researchers covering fundamental research projects as well as epidemiological and clinical projects. The remaining funds are allocated primarily to services at various levels and to travel.

During the latter part of the 1980s, the Swedish Cancer Society was able to broaden its operations and focus more on care development, patient support, information and health education. Amongst other things, aid is given to scholarships for further training of nursing staff and development projects aimed at raising the quality of cancer care.

The Swedish Cancer Society's information provision covers everything from patient brochures and magazine production to nation wide campaigns. Annual campaigns include "Sola sakta" (*Sun safe*) aimed at young children and their parents and the fruit and vegetables initiative targeting the nation's school children.

The Swedish Cancer Society's website is under constant development and plays a key role in disseminating information. For example, it contains brief descriptions of all research projects supported by the Swedish Cancer Society.

The overarching campaign theme for 2003 focused on progress in research and the year opened with a successful TV gala in early January. Tougher rhetoric in our advertising attracted media attention in the spring when the Swedish Cancer Society more clearly criticised the state's lack of support for Swedish cancer research.

The start of the year also saw a change in the post of Secretary General when Ursula Tengelin took over from Marianne af Malmborg. At the same time, Professor Bengt Westermark became the new chairman of the Swedish Cancer Society's research council.

In October, there was a boost in the area of breast cancer when – thanks to a broad partnership – the Pink Ribbon campaign took off in Sweden for the first time. The campaign was carried out with major series of articles in the press, radio and TV features, advertisements, lectures, in-store activities, etc.

26 The highpoint was a gala evening televised on TV4 on 8 October, with 1.2 million viewers and over SEK 27 million raised.

The Pink Ribbon initiative also represents a breakthrough for fundraising via the Internet. A special donations site on the Swedish Cancer Society's website attracted a great deal of attention, as did the result of almost half a million SEK.

For almost ten years now, the society has run its own information and support line, which the public can call for answers to their questions about cancer. The phone number is 020-222 1111. In recent times, the proportion of questions coming in by e-mail has increased considerably, and the number of contacts now totals over 8,000 a year. Four issues of the Swedish Cancer Society's magazine *Rädda Livet* (*Save Life*) were published over the year. In a themed approach, the magazine focused on various cancer diseases and the latest news in research, care and treatment. The Swedish Cancer Society also conducts intensive work to combat the damaging effects of tobacco, for example through education and targeted material for mother and baby clinics.

At the end of the year, a great deal of work went into planning a comprehensive stop smoking campaign which will be launched in spring 2004.

2003 saw the external work intensified through a number of web-based campaigns, not least in the area of tobacco. A stop-smoking site offering the interactive smoking cessation program Pepp continued to attract great attention and had a record number of visitors.

On the political front, our protests continued against the huge increase in overhead costs, as did our work on achieving a nation-wide cancer plan.

The Swedish Cancer Society stresses the importance of being seen as a cancer research council, as state aid for research in the cancer field currently amounts to a mere few percent.

At the same time, the society's role as a player in the research community has become increasingly significant.

Our intensive external work was rewarded at the end of the year with record legacies amounting to SEK 327 million – the largest sum raised in the society's 52-year history. This is an impressive result which will help ensure stability and a long-term approach within the vital system of Swedish cancer research funding

The Swedish Cancer Society secretariat is now located at David Bagares gata 5 in Stockholm. This address houses the departments for finance, research and development plus information and fundraising.

MEMBER ORGANISATIONS



THE FAROESE CANCER SOCIETY (Observer)

FØROYA FELAG MÓTI KRABBAMEINI

Faeroe Association Against Cancer 2003

It is now 24 years since The Faeroe Association Against Cancer was established. It is a private organisation relying on donations from subscriptions, lottery and gifts. The Association is not publicly funded.

The aims of the Association are:

- to provide information about cancer diseases and how to prevent them in various ways
- to support research in connection with cancer
- to provide help and assistance to people suffering from cancer

The Association is governed by a committee of five people and the Chairman is Mr Jákup N Olsen.

The Association employs one person who is an advisory nurse and is also the secretary of the Association. All other work is performed on a voluntary basis.

The Association runs an Advisory Office for which a nurse is responsible. Cancer patients and their relatives can contact the office and get advice, information, help and support. The Advisory Office works with the Health Authorities, the home help, the Social Authorities and other institutions.

These sub-groups work within the Association:

- Self-help groups for patients and relatives.
- "Assistance for help" is an advisory group for women with breast cancer.
- The Stomi group provides advice to people with stomi and pelvis reservoir.
- The parent group provides information for parents of children suffering from cancer.

A social worker is attached to the Association and gives advices and information in social matters.

Psychologist: The Association provides financial support for cancer patients requiring a psychologist.

Financial help: The Association has a support Fund where cancer patients can apply for financial help.

The Faeroe Association Against Cancer has observer status in the NCU and the ECL. In 2001 the Association obtained membership in the Patient Support Group within the NCU.

In the past year the Association has focused on males and cancer. In cooperation with a professional interest group for nurses, working with cancer patients, the Association arranged a public theme-day on the subject led by the Danish psychologist Niels Peter Agger.

The Association has organised courses for persons who do voluntary in the association aiming at improving their abilities to work in supporting people and communicate with relatives in crises and bereavement.

On 31 May, the international tobacco-free day, the Association organised a day of information concerning smoking and the dangers involved in cooperation with the Heart Association and the Preventative Council.

The Association has established its own *Look Good – Feel Better* in the Faroes. This initiative has been successfully working for a year and has become increasingly popular.

Also this year the Association has benefited from the cooperation with the Nordic cancer associations. We are represented in a working group within the NCU Patient Support Group concerning sexuality and on the rehabilitation of cancer patients.

Regarding this we have shed light on the question of rehabilitation in the Faroes. Last summer the Association arranged informative meetings for cancer patients and leaders within the Health and Social Departments on the problem of rehabilitation and recuperation; especially the needs of and the offers to cancer patients in the Faroes and how we can improve the situation.

STATUTES OF THE NORDIC CANCER UNION

28 § 1 Background

The Nordic Cancer Union (NCU) is a co-operative body for the national cancer societies in Denmark, Finland, Iceland, Norway and Sweden.

§ 2 Objectives

The objectives of the NCU are:

- To handle projects and activities within research, information/prevention and patient support, which should be characterised as follows:
 - creating synergy by implementation at a Nordic level
 - being unique through the collaboration between the Nordic countries
 - that the results of the projects should be improved and thus be of a higher standard than if implemented at a national level in the individual countries.
- Exchange of experience and co-operation on national and political issues.
- To strengthen the international co-operation.

§ 3 Board of Directors

1. The NCU is governed by a Board.
2. The members of the Board are the chairmen and the secretary generals of the cancer societies which are regular members of the NCU.
3. The deputy chairmen of the cancer societies are deputy members.
4. The chairman of the research committee is invited to attend Board meetings as an observer. If the chairman is prevented from doing this, the research committee may itself put forward the name of another member as observer.
5. The Board may approve other cancer societies in the Nordic countries attaining the status of an observer.

§ 4 Chairmanship

1. The chairmanship is held alternately by the members for a 3-year period taking effect from the start of a calendar year.
2. The Board decides on the order of priority of the members holding the chairmanship.
3. The Board meets once a year in the country of the member society holding the chairmanship.
4. The meeting, which is held in the spring, covers the following items:
 - discussions of all-embracing general and basic guidelines for co-operation in the NCU,
 - approval of the accounts,
 - adoption of the budget, including the approval of the apportioning index,
 - approval of the annual report.
5. The minutes of the Board meeting are signed by the chairman of the Nordic Cancer Union and the chairman of the cancer society, which is to have the chairmanship for the subsequent 3-year period"

§ 5 Secretariat

1. The chairman of the NCU is responsible for the Union's secretariat function in relation to general matters.
2. The secretariat function is held by the country which holds the chairmanship of the NCU.

§ 6 Committee

- The Board may appoint committees, as required. The Board has appointed the following committees:
- Research committee
 - Patient-support committee
 - Information committee

§ 7 Research Committee

1. The Board makes an annual overall appropriation to the research committee to be allocated for scientific work as the committee thinks fit.
2. The tasks of the research committee include assessing applications for research grants and allocating research funds from the research pool of the Nordic Cancer Union.
3. The Board of the NCU appoints to the research committee one member from each member country put forward by the respective member societies. With regard to the appointment of members, importance is attached to their having wide experience and representing a wide knowledge of cancer research.
4. The secretarial functions of the Research Committee are to be handled by and to follow the chairmanship of the Nordic Cancer Union.

§ 8 Project and work teams

1. The Board may appoint project teams and work teams.
2. For each project team/work team a chairman is appointed by the secretary general group in line with proposals from the members of the project team/work team. In addition, each project team/work team shall include a representative from one of the five member societies.
3. The project teams/work teams report to the NCU secretariat, which is responsible for communications with the secretary general group.

§ 9 Symposia

An annual symposium on scientific themes of relevance to cancer may be held. Decision in this matter are taken by the NCU Board. Researches and others interested in fighting cancer in the Nordic countries can attend the symposia.

§ 10 Finances

1. The NCU's funds are deposited and managed in a separate account by the cancer society which receives the funds, which are placed at the disposal of the Union.
2. The NCU may receive grants and donations, from which it may pay out grants and provide support for projects and activities. Decisions in this matter are taken by the Board.
3. Overheads in connection with meetings arranged by the NCU are met by the cancer society in the country where the meeting concerned is held. However, this does not apply to travel and hotel costs, which are paid by those attending the meeting. The Board may approve the payment of the travel costs incurred by a member organisation in connection with official NCU meetings from the common Nordic kitty, if special circumstances exist.
4. Decisions regarding the apportionment of any overheads not governed by the provisions of the statutes are taken by the Board. Such decisions shall be unanimous and subject to approval by the respective cancer societies insofar as they have to make grants to cover overheads.

§ 11 Signatories

The chairman and the secretary general of a society or two other Board members authorised by the Board may sign jointly on behalf of the NCU.

§ 12 Dissolution of the Nordic Cancer Union

In the event of the dissolution of the NCU, any financial assets owned by the latter shall be distributed among its members in proportion to the apportioning index.

Statutes approved at the Board meeting of the Nordic Cancer Union on 10 May 2001.

THE BOARD OF THE NORDIC CANCER UNION



Kræftens Bekæmpelse



Suomen Syöpäyhdistys



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(Observer)

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ISLANDS (Observer)

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