

Activities of the Nordic Cancer Union

**Annual report
January – December 1998**

**Icelandic Cancer Society
1999**

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A satellite overview of Northern Europe, including the Nordic countries.

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The Nordic Cancer Union 1949-1999

Sigurður Björnsson chairman of the Icelandic Cancer Society

The Nordic Cancer Union (NCU), which soon celebrates its fiftieth anniversary, is an alliance of the cancer societies in the five Nordic countries and since 1988 the Faeroe Islands Cancer Society has enjoyed an observer status. The purpose of NCU, as stated in its statute, is to promote the members' mutual work in the fight against cancer. Due to cultural, economical and health care system similarities as well as close ties between the Nordic countries, a cooperation in cancer research, prevention and treatment seemed like something that might be fruitful and justify the effort of forming and keeping together a union of the national cancer societies. Have the dreams and expectations of the founders come true, has the effort been worth while? Should we continue for another 50 years?

Before we answer these questions let us look back for a minute and see what, if anything, has changed.

In 1949 cancer was a dreaded disease. Little was known about the causes of most cancers and treatment attempts were often futile. Very few cancer registries had been started and cancer

epidemiology was in its infancy. Acute leukemia and advanced stage lymphomas were almost invariably fatal, solid tumors were often diagnosed at a stage where surgery and radiation therapy could only offer palliation. Cancer had replaced tuberculosis as the most feared of diseases.

What was badly needed was faith and belief that cancer could be dealt with and conquered in an organized and scientific fashion. In order to achieve that goal the causes for cancer had to be looked for, the incidence recorded, the behaviour studied and new diagnostic and therapeutic modalities developed. Those with foresight realized that in order to achieve these goals faster it would be sensible to pool resources and join hands. I believe that it was in this spirit that NCU was formed. Now there are some 25 million people living in the Nordic countries, enjoying some of the best health care systems in the world, contributing to and enjoying the fruits of medical research and living longer than most nations.

Several important contributions in the battle against cancer have been made in the Nordic countries during the lifetime of NCU:



Sigurður Björnsson, chairman of The Icelandic Cancer Society from 1998 and a member of the board from 1980. Consultant in oncology at the Reykjavík Hospital.

1. The Nordic cancer registries are second to none and have generated the basis for high quality epidemiological research.
2. Organized, and in some Nordic countries nationwide screening for cancers of the uterine cervix and breast, developed through pioneering and meticulous research has proven effective and gained international recognition.
3. Major achievements have been made in the areas of basic research and treatment of the various cancers, many through collaboration between institutions in the five countries. The NCU Cancer Research Fund specifically stipulates that researchers, applying for support, must work together with colleagues in at least one other Nordic country.
4. A very significant and varied contribution for many years in the campaign against tobacco use, e.g. with NCU's project "Children and passive smoking" and lobbying against tobacco advertisements.
5. Recognition of the importance of psychosocial issues and palliative care in the comprehensive management of patients with cancer.
6. Increased emphasis on communication skills, both interdisciplinary as well as between caregivers and patients and their families. NCU has provided training opportunities in these areas.

The Nordic cancer societies and NCU have made it a priority to support cancer research, both within their own organizations and through research grants. The funds have been raised by various means, mostly through public campaigns or contributions. This environment for cancer research may now be about to change.

New discoveries in biological sciences and computer technology have paved the way for research adventures never before imaginable,

especially in the areas of molecular biology and genetics. A race is on between large industrial biotechnology companies, which are willing and able to invest huge amounts of money and effort to try to solve biological mysteries, never before possible. All of a sudden medical data, genealogical information and biological specimens are becoming very valuable commodities. Physicians, health care institutions and health authorities are being offered payments, shares in biotechnology companies or royalties in potential future valuable discoveries or remedies in return for access to patient data and samples. It may be difficult to uphold traditional values concerning patients' rights, confidentiality and medical ethics when economical incentives and job opportunities for scientists are being offered. The influx of money from this direction could also possibly adversely affect the raising of funds for research from conventional sources thereby hampering research in other areas of cancer.

It is my belief that the need for national cancer societies in the Nordic countries and the pooling of their strength in the Nordic Cancer Union is no less necessary now than it was almost fifty years ago. The scenery has changed. Cancer is still a dreaded disease although major victories have been won. The fight against cancer is a scientific challenge and many basic questions will be solved in the laboratory. We must, however, remember that each case involves a human being and his or her family.

I believe that NCU and the member societies will continue to play a major role in promoting cancer education, prevention, basic and applied research as well as cancer patient advocacy and support in the years to come. I think the founders would agree with that.

We thank them for coming up with a splendid idea.

An annual report on the activities of the Nordic Cancer Union during the period from January to December 1998

THE ORGANISATION AND ACTIVITIES OF NCU

The activities of the Nordic Cancer Union (NCU) are now reported for the whole year 1998. This is in accordance with a decision that the annual exchange of the rotating responsibility for the Union's leadership and secretariat between the five Nordic countries should be at the end of each calendar year.

The annual rotation of the administration used to take place in the summer, usually in August. Iceland took over the administration from Norway in September 1997 and covered the interim period until the end of 1998.

MEETINGS

The Secretary Generals and the directors of the Nordic Cancer Societies, who are responsible for the co-ordination of NCU's co-operation on a day-to-day basis, **held three meetings and two telephone meetings in 1998.**

They have decided to hold regular joint meetings with professional groups concerned with different activities within the Nordic Cancer Societies. This is in order to be able to follow more closely the various co-operative efforts undertaken by the NCU and to learn from experiences and practices within the different national societies.

According to this plan, the Secretary Generals had joint meetings with the chiefs of information of the Nordic cancer societies in Iceland in October 1997 and with the chiefs of finance and fundraising respectively in February 1998. During these very useful meetings the various different practices of financial administration and turnover and book-keeping were compared and discussed as well as the financial affairs of the NCU. Furthermore, the national societies different fundraising methods were discussed, together with pending new NCU fundraising projects and ethical questions in this context.

The NCU's annual board meeting was held in The Icelandic Cancer Society's headquarters in Reykjavík, Iceland on 12th June 1998 in

accordance with the administrative changes now taking place within the NCU. Apart from traditional matters dealt with at such meetings and discussion of new projects of co-operation, the board confirmed its earlier resolutions concerning the administrative functions. *The Union's leadership and the responsibility for the secretariat* will continue to be passed from one member country to another at the end of each year and will now follow the calendar year.

However, the responsibility for the *NCU research-secretariat*, which is separate, will stay with each national cancer society for three consecutive years before passing on to the next society. It will thus remain in Norway during 1999. The chair for the research committee will, however, change on an annual basis, as it will be held by a representative of the country responsible for NCU's administrative secretariat. Therefore the chairman will be Swedish for 1999.

The annual board meeting should be held early in the year, at the latest in spring, when the annual report, financial accounts and grants from the Nordic Cancer Union's Research fund are available. However, the timing of the NCU symposium is flexible, and does not necessarily have to be in connection with the annual board meeting. The representative of the host country on the research committee is invited to attend the board meeting as an observer while the committee finds a proxy if the person is unable to attend. In the administrative interim period the advertisements for grant applications will be postponed until the year 2000, - whereas continuing commitments to ongoing projects will be fulfilled. *The annual symposium followed the annual board meeting on 13th and 14th June in Hveragerði, Iceland* with active participation by the Nordic Cancer Registries, who also had their annual meeting concomitantly. This year the theme was: "*Genetics and Environment in Cancer Epidemiology*". There were sessions on Genetic Epidemiology of Breast Cancer, Mutagenesis and DNA Adduct/Studies of Heredity and Environment, Genetic Polymorphisms and Cancer Susceptibility and Ethical Problems of Genetic Counselling. The symposium was professionally

successful with a good attendance of more than 70 scientific participants.

The Secretaries General then held a joint meeting with representatives from the Nordic Cancer Registries in October in Iceland where earlier co-operative projects were analysed and new possibilities of co-operation discussed. It was decided that the Association of the Nordic Cancer Registries (ANCR) and NCU should, preferably, synchronise their annual board meetings and especially their symposia in order to continue and strengthen their previous fruitful co-operation.

The Faeroe Islands Cancer Society has participated in annual board meetings since 1988 with observer status. From now on, the observer status will also apply to the meetings of the General Secretaries.

It was decided that NCU should take the initiative to arrange a *Nordic Summer School in Clinical Research*, similar to the successful arrangement of the Nordic Summer School in Cancer Epidemiology. A working group is responsible for the project. Although originally planned in 1998, it will be postponed until 1999.

NCU celebrates its 50th anniversary in 1999. It has been decided to write the *history of NCU* to mark this occasion. It will cover the period from the foundation in 1949 to the present. The writing is proceeding well. Unfortunately, many of the pioneers have already left us, but two of those who participated early on have agreed to contribute, Niilo Voipio from Finland with assistance from Halldóra Thoroddsen from Iceland. Secretarial help will be provided by Sirkka Liisa Neiman from Finland. Liisa Elovainio, the secretary general of the Cancer Society of Finland, will write a review of NCU's activities during the last 10 years and supervise the task.

After much hard work and preparation the Norwegian Cancer Society was in 1998 shown the well deserved honour of being elected to host the International Cancer Unions 18th International Conference. This will be held in Oslo during the first week of July 2002. This International Conference has never before been held in a Nordic country and the responsibility of hosting this event will undoubtedly motivate the Norwegian Cancer Society to demonstrate yet again their significant commitment in contributing to cancer-related work both at home and abroad. The Norwegian Cancer Society is the first of UICC's member societies to decide to give 1% of its disposable means to international projects within UICC's support programs. The other members of NCU will, of course, do what they can to assist in making this conference a success.

THE INFORMATION FIELD

In 1998 this field has continued to expand and three meetings were held. There was one joint meeting with representatives from the fundraising and finance departments of the national societies, where the questions of fundraising and sponsorship were discussed.

Work will continue on the project "Children and passive smoking", now with the title "Barriers in prevention against tobacco within the health service". It investigates how doctors in primary health care talk to their patients about their eventual use of tobacco, and the barriers doctors experience in their preventive work. An investigation is ongoing in all the Nordic countries.

Another joint ongoing project is an investigation of the screening activities with mammography and for cervical cancer. This is in order to produce a joint information package on letters of invitation for screening, with an eye to increasing the rate of attendance. This project is led by dr. Iben Holten at the Danish Cancer Society.

Furthermore, a joint effort has been made to lobby against tobacco advertisement within the European Union. The Cancer Societies of Europe succeeded together with other organisations in pushing through a ban on the majority of advertisements for tobacco and sponsoring of tobacco producers. Although the margin was the narrowest possible, it was a big step forward in the campaign against tobacco.

THE PATIENT SUPPORT FIELD

There are various ongoing projects within this field, and others that have been completed. A project focussing on *Improving doctors' skills with regard to patients' psycho-social needs* started up in 1993. Under the auspices of NCU, 21 doctors from the Nordic countries have been educated as teachers, and they have now completed 37 courses attended by a total of 230 doctors. A partial evaluation of the courses has been published (Acta Oncologica vol.35, No.2, pp 246-248,1996) but a final evaluation report, by Arnstein Finset and Knut Aspegren, will be issued in the spring of 1999. Follow-up activities are planned or in process in all the member countries but the project will be concluded on behalf of NCU in 1999. In connection with this project a very successful course on doctor-patient communication was held in the Faroe Islands, 27th - 29th March 1998 for 8 participants, Faroese doctors and nurses. The instructor was Anders Bonde, a medical doctor, trained as a teacher under the NCU scheme.

A *textbook in communication* used at the courses in communication arranged by NCU,

"Talking to Cancer Patients and Their Relatives" by Ann Faulkner and Peter Maquire, has been translated into Danish, Norwegian, Swedish and Finnish with NCU support. The translated versions have been published in Denmark and Norway and are expected to be available in Sweden and Finland in 1998.

After a Nordic workshop in 1996, arranged by NCU on *psychosocial units*, follow-up activities have started to support the establishment of such units in Finland and Iceland. These activities are ongoing and the project is expected to conclude in 1999.

With the co-operation of the Nordic Association for Palliative Care, a panel of experts has worked out a proposal for a *Nordic model of multidisciplinary courses in palliative treatment*. These courses are intended to give professional merits to participants. The courses include a short-term and a long-term aspect and have been given NCU support to hold a "Teach the Teacher" course early in 1999.

The conference on patient support in Oslo 1997 has been followed up by two related projects:

Firstly, *a workshop, primarily for social workers on the theme: Cancer and means of living/quality of life*. The workshop was held 11th - 13th September 1998 in Oslo, attended by 70 participants with a varied professional background, but mostly hospital social workers.

Secondly, an expert group has been appointed to evaluate the *standards of education and training programmes for voluntary workers*, and what level of co-operation they have with professionals. Proposals for a manual could be discussed by national workshops at the end of 1999 or early 2000. Furthermore, an expert group is planning a *workshop under the auspices of the NCU about the patient's choice in connection with clinical trials*. This is awaited at the end of 1999.

THE RESEARCH FIELD

The field of cancer research is one of the most important for the Union and in 1998 the Research Committee *allocated grants to the total amount of 5,6 million NOK* to 17 chosen Nordic co-operative projects. There were 42 applications, this time for a sum of more than 27.7 million NOK. The members of the Research committee agree that their quality remains of a high standard and is improving year by year. To obtain a grant, the application has to meet "peer review" criteria, where Nordic relevance and synergism have to be obvious. The scientific level of the project and its connection

with cancer is also of great importance, as are the scientific accomplishments of the applicant.

NCU's co-operation on research was discussed and reviewed during the year of 1998, both by the NCU board and by the Research committee. As previously described it was decided that the Research secretariat, which is separate from the general secretarial function, will rotate between the national societies after three years. It will thus remain in Norway in 1999. The chair of the research committee will therefore change annually and come from the member country responsible for the secretariat that year. In 1999, the chair will be from Sweden.

In recent years, NCU has also supported UICC's cancer research programmes via *ICRETT fellowships*. In 1998 the amount granted was US dollars 30,000.

ECONOMY

The Nordic Cancer Union's financial year follows the calendar year. A special "*distribution key*" is used to distribute the cost of the various co-operational activities between the member countries. This was the distribution in 1998, the same as the previous year:

Denmark	30.4%
Finland	5.0%
Iceland	1.0%
Norway	18.4%
Sweden	45.2%

Each country's share of the costs is decided on the basis of the income acquired by each of the national societies after deduction of public subsidies, if any, and the costs of the fundraising. The NCU budget for 1998 was NOK 7,926.907.00.

Table 1. Research grants from NCU in 1998

Main applicant	Title of Project	Countries of co-operation
Alvegaard, Thor Andreas	Scandinavian Sarcoma Group (SSG) – Centralized Registration – An SSG Musculoskeletal oncology research and multidisciplinary approach	D, F, N, I
Andersen, Aage	Occupational Cancer in the Nordic countries	S, D, F
Anderson, Harald	Statistics and data management in Scandinavian Breast Group clinical trials; travel and meeting expenditures for the Statistical Committee	D, F, N
Dillner, Joakim	Continued Prospective epidemiological studies of human Papillomavirus infection	N, I, F
Geisler, Christian H.	Nordic Lymphoma Group: An application for support to a continuing collaborative research effort into the treatment, biology and epidemiology of malignant lymphoma in the Nordic countries.	N, S, F, I
Gimsing, Peter	Effect of intravenous bisphosphonate on skeletal morbidity and health-related quality of life. A prospective placebo controlled study including a “cost-utility” analysis.	N, S
Hakama, Matti	Etiological factors of prostate cancer; A longitudinal nested case-control study	S, N, I
Heyman, Mats	P15ink4B and p16ink4 gene inactivation as a prognostic marker in childhood ALL	D, N, F
Kogner, Per	Neuroblastoma therapy, biology and epidemiology. A cooperative Nordic study	N, D, F, I
Lindblom, Annika	Mutation analysis, predictive testing and localization of additional genes responsible for hereditary colorectal cancer	F, D
Lindblom, Annika	Screening for mutations in breast cancer genes	N, I
Mandahl, Nils	Genetic changes in bone and soft tissue tumors	F, N
Mork, Jon	A joint Nordic cohort study of virus infections as a risk factor for squamous cell carcinomas of the head and neck	S, F
Nevanlinna, Heli	Genetic basis of hereditary breast cancer in the Nordic countries	S, I
Saatcioglu, Fahri	Dissecting the role of androgens in the molecular biology of prostate cancer	F
Ringborg, Ulrik	Resection margins of 2 versus 4 cm in cutaneous malignant melanoma with a tumor thickness of >2.0 mm	D, N, Est og Lat
Sørensen, Jens Benn	Neoadjuvant chemotherapy in non-small cell lung cancer stage IIIA Application for coverage of administrative costs in running the 2 protocols on T3 disease and N2 disease in Denmark, Norway, Sweden and Finland.	N, F, S

Reports on the activities of the Nordic Cancer Societies from January to December 1998

THE DANISH CANCER SOCIETY

KRÆFTENS BEKÆMPELSE

The Danish Cancer Society celebrated its 70th anniversary on 23 October 1998. We marked the occasion with great festivity in our local units. We had open house at the main office in Copenhagen and more than 500 people visited the Danish Cancer Society. Also, at the State University Hospital in Copenhagen and at Herlev Hospital there were special arrangements in honour of the occasion.

The Danish Cancer Society puts great emphasis on the political aspect of its work. We consider ourselves to be the mouthpiece of cancer patients. One of our primary objectives has been to open the eyes of politicians to the fact that here in Denmark cancer incidence and treatment trends are heading in the wrong direction. Danes get cancer more often than people in the countries with which we usually compare ourselves, e.g. the other Nordic countries and the European countries surrounding us. The same unfavourable tendency is also seen in the survival rate. The survival rate is lower in Denmark, and unfortunately there is no indication of any improvement - in fact, the reverse is true.

This is of course an unacceptable situation for Danish cancer patients. Therefore the Danish Cancer Society has made a point of highlighting these issues. In the autumn of 1998, we took an active part in a media debate concerning cancer treatment in Denmark, and we succeeded in creating a dialogue with members of the Danish Parliament and politicians in the counties. The result is that the Danish Minister of Health has stepped in and set up a steering group, of which the Danish Cancer Society's chairman is a member. The Minister of Health has decided that this steering group shall prepare a national strategy for cancer. The Danish Cancer Society has been working in favour of this for a very long time.

We are quite satisfied with this initiative, and it is an important task to seize this opportunity to improve conditions for Danish cancer patients.

In 1998, the Danish Cancer Society's expenditures were distributed as follows: approx. 61% for research, approx. 20% for patient support, and approx. 12% for information purposes. The Danish Cancer Society finances approximately half of the cancer research in Denmark. The contribution to cancer research is made up partly of project grants, which are granted upon application to both scientific and psychosocial cancer researches. The remaining part goes to the running of the Danish Cancer Society's own research departments, both within biological and epidemiological cancer research. Researchers at the Danish Cancer Society apply for grants on equal terms with researchers outside the Danish Cancer Society.

Our research has been excellent this year, with both small and great advances. It is impossible to mention all results here, but some examples should be mentioned. Within epidemiological research, one researcher has obtained a Ph.D. degree by showing that 4 hours of exercise a week will decrease the risk of getting colon cancer by 50%, whereas the risk of getting oesophageal cancer will be reduced by 65%. Another project rejects the fear of traffic pollution causing cancer among children. The incidence of cancer is not higher for children, born or unborn, living in an area with heavy traffic.

In biological cancer research 'methylation' was one of the keywords in 1998. Researchers have developed a new method to determine which genes have methylized as this may turn a normal cell into a cancer cell. Doctors have known a possible treatment for a long time, but until now they have not known which patients would benefit from the treatment. However, researchers are now able to make a genetic diagnosis showing which patients the medicine will help. Another important project has provided new knowledge on some HPV-viruses, which are sexually transmitted and cause cancer. This project gave one of our researchers a D.Sc. degree.

The work with our patient support is performed through 5 counselling centres, 3 county centres, financed partly by the county in question and the Danish Cancer Society, and 5 smaller units that

provide psychosocial support for cancer patients and their families. Our goal is to have a counselling centre in each county. The counselling centres provide employees e.g. in the health sector with training, supervision, knowledge and experience about social and psychosocial problems concerning cancer patients and their families.

We have finalized a major project on the needs of relatives. Palliation, including the establishment of hospices and palliative units, is an area of high priority. We wish to ensure that terminally ill patients and patients with an advanced disease receive treatment and qualified palliative care. At the end of life, the perspective of the illness may lack importance whereas the experiences and views of the patient and his or her relatives are of greater importance.

Many activities were set up in the area of prevention and information in 1998. We have initiated a project on "Young People and Smoking" aimed at young people aged 16-19. A study showed that 17% of pupils smoke in their first year of high school, 23% smoke in business schools, and 43% smoke in technical schools. These figures show very clearly that something has to be done, especially in the technical schools.

A new Danish study deals with the advantages of eating more fruit and vegetables. The report estimates that the risk of cancer and vascular diseases could be reduced by 15-30% by eating 600 grams a day. Therefore the Danish Cancer Society, the Danish Heart Foundation, the National Board of Health and a chain of grocery stores

recommend the population to eat 600 grams of fruit and vegetables each day. The slogan "six a day" will be used in a future campaign aimed at increasing the consumption of fruit and vegetables.

The Danish Cancer Society, the National Board of Health and the EU Commission launched a joint project called "Men and Cancer". Through TV and radio spots and a pamphlet we focused on the symptoms of male cancers. The aim was to make men more aware of the warning signals and to make them see their doctor at an earlier stage. The campaign was covered well by the press and it proved that much more information is required regarding men and their types of cancer.

In 1998, the Society had 254,940 personal members. The net income of the Danish Cancer Society amounted to 282 million DKK whereas the greatest source of income was testamentary gifts and legacies amounting to 107 million DKK. Furthermore, a number of lotteries are arranged every year, which in 1998 brought in approx. 48 million DKK. Other sources of income are membership fees, house-to-house door-knocking campaigns and capital investments. The Danish Cancer Society is represented in 268 out of 275 municipalities with local units and committees. The rate of coverage is thus 97.8%.

In May 1998, the Danish Cancer Society went on the Internet with a home page. From May 1998 to March 1999, our home page has had 35,000 visits. For further information concerning The Danish Cancer Society, please contact www.cancer.dk



The Secretaries General of NCU had a meeting in Iceland on 24th October 1997 when this picture was taken.

From left to right: Guðrún Agnarsdóttir and Halldóra Axelsdóttir secretary from the Icelandic Cancer Society, Ninna Würtzen from the Danish Cancer Society, Liisa Elovainio from the Cancer Society of Finland, Marianne af Malmberg from the Swedish Cancer Society, Lilly Christensen from the Norwegian Cancer Society and Jákup N. Olsen from the Faroese Cancer Society.

THE CANCER SOCIETY OF FINLAND

CANCERFÖRENINGEN I FINLAND SUOMEN SYÖPÄYHDISTYS

The Cancer Society of Finland is a public health organization that provides services at national level. It is a national central body for 16 member organizations, all of which are registered. Twelve of the member organizations are provincial cancer societies, and four are national patient organizations (LE Invalids, an association for patients with laryngeal or oral cancer; the Finnish Association of Cancer Patients; SYLVA, a society for parents whose children suffer from cancer and the Association of Prostate Cancer Patients). In addition, the member organizations have appr. 200 unregistered divisions and clubs. Roughly 2% of the population (141 000 Finns) are members of cancer organizations.

The Cancer Society of Finland engages in health promotion, provision of cancer-related information and the organization of mass screenings to prevent cancer. The Society maintains cancer outpatient departments, and cytological and histological laboratories. It also supports scientific research on cancer.

For over 30 years, women between 30 and 60 years of age have been subject to systematic screening for prevention of cervical cancer. All of these women have received an invitation to a Pap smear test every five years. The quality control of cervical cancer preventive screenings was improved, when the Finnish Foundation for Cancer Research provided a Papnet Testing System, the technology of which is based on the neural network. The Papnet is linked to the premises of the department of gynecology in Helsinki University Central Hospital. In the year 1998, the increasing incidence of cervical cancer that had been noticed during the four previous years seemed to level off.

The national breast cancer screening program has been continuing in Finland 12 years. During that time over 1,7 million women have received an invitation and almost 90% of them have complied. Over half of the screenings in Finland has been organized by the Cancer Society of Finland and its member organizations.

At the end of the year 1998 the Cancer Society of Finland had six outpatient departments and five pathological laboratories. Most of the customer calls of the six outpatient departments were connected to the screenings.

The Cancer Society received a grant from the Finnish Slot-Machine Society for scientific evaluation of the Finnish screening program.

The Finnish Cancer Foundation had its 50th anniversary in 1998. To celebrate this year the Cancer Foundation organized a fund-raising campaign, which reached every household in Finland. The net profit of this jubilee campaign was FIM 4,1 million. The Foundation also received many additional donations and legacies. Cancer research funding rose to FIM 12,5 million in 1998.

The theme of the European Week against Cancer was *Cancer in men* and many grants were provided to prostate cancer research.

The research institute carrying out statistical and epidemiological cancer research within the Cancer-organizations is the Finnish Cancer Registry. It works under the National Research and Development Centre for Welfare and Health (STAKES). The Cancer Society of Finland provides technical support (staff, premises, funds) to the Registry. The Finnish Cancer Registry has two areas of activity that complement each other: it collects information about the occurrence of cancer in Finland and prepares annual cancer statistics on the basis of this information, and it conducts epidemiological and statistical research on cancer. The effect of mass screenings is one of the subjects of this research. The Registry has a tradition of high-level research and know-how, and good connections with universities and other research institutes. It is also an internationally recognized research institute.

The Cancer Society of Finland publishes a bulletin, *Syöpä-Cancer*, issued six times a year. The bulletin has grown over a period of 30 years. Its purpose is to convey current and reliable information about cancer. It also discusses problems relating to health care from the point of view of cancer patients. The circulation is 134 000.

Since 1992, the Cancer Society of Finland has had a free telephone service. Bilingual personal telephone counselling, *Syöpäyhteys-Cancerkontakt* (Cancer Contact), has been found to fill a substantial need. The line is open for two hours daily. In 1998, 2005 calls were received. The service has provided support to cancer patients and helped persons wanting more (knowledge and) information. We have put more emphasis on counselling and listening over the preceding year, and we have seen a rise in the number of questions about treatment, which accounted for 28% of calls.

The cancer organizations also provide hospice services for cancer patients, with 66 beds, and home-care services. The hospices aim primarily to alleviate the symptoms of terminally ill patients and provide support for their next of kin. Day-

hospitals represent a new form of activity. Day-hospital doctors also work in home care. Day-hospital, home-care and wards form a well-functioning chain in which patients can familiarize themselves with activities in the day-hospitals, receive care at home, and subsequently be admitted to a ward. Patients' relatives have taken an active part in patients' care, and some have availed

themselves of the opportunity to stay overnight in the patients' rooms.

The year 1998 has also been a year with many international activities. The presidency and secretariat of the Association of European Cancer Leagues (ECL) is currently in the Cancer Society of Finland.

For further information concerning the Cancer Society of Finland, please contact www.cancer.fi



Pictures from NCU's annual board meeting, held in the headquarters of the Icelandic Cancer Society in Reykjavík, Iceland 12th June 1998.

From centre to left: Liisa Elovainio and Risto Johansson from Finland, Lilly Christensen from Norway, Jákup N. Olsen and Jansy Gaardlykke nurse from The Faroe Islands, Sigurður Björnsson, Guðrún Agnarsdóttir and Margrét Ormslev secretary from Iceland, Jens Kr. Gøtrik and Ninna Würtzen from Denmark, Göte Långberg and Kenneth Nilsson from Sweden.



From left: Margrét Ormslev, Jens Kr. Gøtrik, Ninna Würtzen, Göte Långberg, Kenneth Nilsson, Liisa Elovainio, Risto Johansson, Lilly Christensen, Jákup N. Olsen, Jansy Gaardlykke, Sigurður Björnsson and Guðrún Agnarsdóttir.

THE ICELANDIC CANCER SOCIETY

KRABBAMEINSFÉLAG ÍSLANDS

The Icelandic Cancer Society was established in 1951 and from the beginning the society's aim has been to support the fight against cancer in every possible way. The activities of the society during almost half a century, have been very fruitful and shown remarkable results. With time, this voluntary organisation has developed into a national association consisting of 29 regional divisions, including cancer patients' self-help groups with a membership around a total of 10,000. At the same time the society is also an institution with multiple functions that plays an important role in the Icelandic health service, with about 144 employees filling just under 70 jobs, as many work part-time. This development would never have been possible if The Icelandic Cancer Society had not received support from the Icelandic people who have had high regard for the society from the very beginning. The society's activities are primarily financed by donations, income from sale of lottery tickets, sale of remembrance cards and badges and other fundraising activities. We had some important donations during 1998, e.g. a bequest from an Icelander who lived most of her adult life abroad. For this we are very grateful. In 1998 we focused on a special fundraising campaign among the users of VISA and EURO credit cards. The society already gets regular support from a number of cardholders who contribute a monthly sum through their card. We wanted to increase the size of this group and succeeded in doing so with a publicity campaign and the goodwill of the relevant credit card companies. The health authorities are another source of income, through an agreement with the Cancer Society which organises a Cancer Detection Clinic and carries out a nation-wide screening programme for cervical and breast cancer. Our recent agreement with the Ministry of Health runs out at the end of 1998 and we are in the process of negotiating a new one.

The society's income in 1998 was 289.519.168 million Icelandic kronur, or 30.737.782 million NOK.

As the projects of the Cancer Society become more numerous and more demanding, finding the funding for these ambitious activities becomes more difficult.

The Cancer Society has long been responsible for **educating the public about cancer**, for example we have long conducted an educational programme on the dangers of smoking in Icelandic

schools. We have now taken a new approach. The instructors of the Cancer Society have translated and adapted a new Norwegian anti-smoking curriculum for Icelandic primary schools. This will be run by teachers who have received preparatory training courses from our instructors. The Cancer Society will follow closely the success of this new curriculum in schools as our anti-smoking efforts have always been focused most strongly on children and young people. We also offer advice and guidance on creating smoke-free places of work. These are now becoming more a rule rather than exception, including all the hospitals. We congratulated our new president early in January on his commendable decision to keep the presidential home and house of official reception smoke-free.

The Society awarded eight grants to Icelandic scientists engaged in cancer research, in December as usual, from its **two research funds**. Three grants were also given from another separate fund established in favour of children with cancer. The society's **Molecular and Cell Biology Laboratory**, celebrated its 10th anniversary in March with a conference and a well attended open day. Although engaged in various projects related to cancer, the laboratory's main emphasis has been on breast cancer research, resulting in noteworthy contributions published in high-quality international scientific journals. The laboratory's biological bank continues to grow and now has specimens from over 4000 individuals. **The Icelandic Cancer Registry** is run under the auspices of the Society, and negotiations are still under way with the health authorities to take a larger financial responsibility for this valuable data bank. The Society continues to store an important collection of diagnostic tissue specimens in paraffin cubes from at least 3 generations of Icelanders all the way back to 1920 belonging to the Department of Pathology at the National Hospital of Iceland. Although Iceland has a small population it offers a unique situation for modern cancer research, characterised by the ease with which detailed, reliable information about patients, their diseases, risk factors and molecular biological and genetic research can be co-ordinated. All these factors together present a unique opportunity for molecular epidemiological research with the participation of a whole nation. Research workers from the Molecular and Cell Biology Laboratory and from the Cancer Registry are currently holding a large grant of \$550,000 from The United States Army for this very type of research on breast cancer.

But the same **unique research situation** has not escaped the notice of industrial biotechnology

companies, which are ready, willing and able to invest huge amounts of money and effort, with the support of venture capital and financial pacts with pharmaceutical firms, in trying to find the genetic causes of various diseases. Their arrival on the scene has enabled many, well-educated, young Icelandic scientists to return to Iceland to work in this dynamic field. Medical data, genealogical information and biological specimens are now becoming very valuable commodities. The Icelandic Cancer Society has already been approached by two such companies based in Iceland with a view to collaboration in cancer research and we have spent some time discussing these possibilities. However, a completely new dimension was introduced by passing through the Althing, the Icelandic parliament, a highly controversial bill of law on a data base to hold medical information on the whole of the Icelandic nation, without informed consent. This is to be collected and monopolised by a private, biotechnology company intending to sell relevant access to the data bank to different interested parties, e.g. pharmaceutical or insurance companies. The management and researchers of the society have been actively engaged in the general discussion about this bill of law, and were furthermore able to express their comments and concern before the parliamentary health committee.

The Society's **Cancer Detection Clinic** continues regular nation-wide screening of women for cervical cancer (20-69 years) and breast cancer with mammography (40-69 years). The whole screening programme is organised and carried out by The Cancer Society but financed by the health authorities through a six year agreement at a time with the Society since 1988.

The Society's annual spring screening day for skin cancer was on the 1st of May in successful co-operation with dermatologists.

Contributing to the care of cancer patients.

The Society has in recent years considerably increased its support for cancer patients. There continues to be a great demand for the four flats that we have purchased in partnership with the Icelandic Red Cross and are run by the State Hospitals. They are for cancer patients from the countryside who have to come to Reykjavík for diagnosis and treatment. These flats that are

spacious and conveniently located can house patients and their families and have turned out to be a welcome and significant means of support for cancer patients.

There is a continuously growing demand for our **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. Three medical doctors and seven nurses work in this specialised, charitable service. It is inspired by the ideas of the Hospice movement and combines symptomatic treatment with care and sensitivity for the needs of both the patient and his family during this period. The plans for the first Hospice unit in Iceland are underway with expectations of opening sometime early in 1999. The Icelandic Cancer Society is discussing with the State hospitals the possibility of future co-operation between the society's Home Care Service and the Hospice unit.

The society has introduced a **telephone information and support line** for cancer patients, their families and friends and for health personnel. The line has now been running for three years, and the number of calls it receives is growing. Incoming calls are recorded all day but they are answered by two experienced cancer nurses for a couple of hours every day.

Our **annual Health run** for the public was held in June as usual. It attracted only about 600 people this year, due to the fact that Akureyri, Iceland's second biggest town did not participate. In addition, we are facing competition from many other organisations arranging similar events as jogging and running has become a very popular leisure activity in Iceland in recent years.

Our chairman of the Board, Jón Þorgeir Hallgrímsson, wished to step down at the annual general meeting after many years of valuable voluntary contribution, first to the Reykjavík chapter of the organisation and then as a chairman for the society during the last 6 years. He was appointed to the society's honorary board and replaced by Sigurður Björnsson, an oncologist who has also been an active volunteer with the society for a long time, in recent years as a deputy chairman of the board.

For further information concerning The Icelandic Cancer Society, please contact www.krabb.is

THE NORWEGIAN CANCER SOCIETY

DEN NORSKE KREFTFORENING

A year of follow-up and implementation.

The Norwegian Cancer Society embarked on its work in 1998 with enthusiasm. It was important to show that the Society was worthy of the trust reflected in the record outcome of the TV-campaign '97, and fulfil the public's expectations. It was a heavy responsibility to administer the funds that had been made available to us, and it is only natural that the year 1998 was marked by efforts to follow up the campaign.

The TV-campaign funds made it possible for the Society, while continuing its ordinary activities, to allocate considerable sums of money to important projects within the fields of patient-oriented research and patient care, and to the preventive work it considers so important. In addition, 10 per cent of the funds from the campaign were earmarked for international projects. The largest share is to be used to combat cervical cancer in South America, but funds have also been granted for various projects in Russia, for example in Archangel and Moscow, and for a children's sanatorium in Minsk. The Norwegian Cancer Society has also released NOK 1 million of the campaign funds for co-operative research within the field of alternative, or complementary, medicine, in an attempt to bring more clarity into the dialogue between the representatives of conventional medicine and the proponents of alternative forms of treatment.

We have noted with pleasure and with gratitude that the support for the fight against cancer has not died out after the effort in autumn 1997. In spite of the record support for the TV-campaign, several appeals for help in the wake of natural disasters, and constantly increasing competition for donors, 1998 was another very good year for the Norwegian Cancer Society, with, for example, an increase in legacies and memorial bequests. This implies that we can continue to address urgent problems in the fields of research, patient care and cancer prevention, and meet our long-term commitments to various research projects of several years' duration. It also means that the Norwegian Cancer Society can continue to act as a driving force for broad-based cancer research of high international standard in Norway, to ensure optimum diagnosis and treatment of cancer.

Several of our patient support centres experienced more inquiries in 1998 than in earlier years, and more of them were from men. This may

be due to the establishment of contact groups for men with prostate cancer. The "Europe against Cancer" campaign, focused in 1998 on men with cancer, and twice as many men as normal rang the Cancer Help-Line during the campaign period. More staff on the Help-Line, and longer opening hours, led to a 40 per cent increase in inquiries.

This year marked the ten-year anniversary of the merging of the two earlier cancer societies, the Norwegian Society for Fighting Cancer (founded in 1938) and the Norwegian Cancer Society (founded in 1948). There is no doubt at all that in 1998, marked progress was made in the fight against cancer through a number of important events which gave the Norwegian Cancer Society a steadily stronger profile in society. The cancer-related work administered by the public authorities has received a tremendous boost through budgetary allocations based on the Norwegian Cancer Plan. The Norwegian Cancer Society took the initiative for such a plan in 1994, and allocated NOK 1 million towards its preparation. The result was a concrete plan to strengthen the cancer-related efforts in Norway, with associated appropriations over the State Budget, estimated to more than NOK 2 billion over a period of five years.

During the year the Norwegian Cancer Society published a book on cancer research in Norway, containing a list of all research fellows paid by the Society during the period 1938-1992, and a brief description of their projects. The book shows that the Society's support has been of inestimable importance to a large number of persons who are, or have been, active participants in Norwegian research.

In 1998, because information on cancer prevention is perhaps the most important means of reducing the disease, the Norwegian Cancer Society, in co-operation with other health-promoting organisations and the public authorities, has made a special effort to encourage a healthy diet among the population. The efforts to prevent injury from tobacco were similarly intensified, and the Society can refer to good results from a campaign directed at pupils in the lower secondary school. The already established "BE smoke-FREE" programme included about 50 000 pupils in the 8th and 9th grades in 1998, distributed between about 2000 schools. This means that our goal of reaching one third of all the classes in the lower secondary school has been exceeded by more than 50 per cent.

In 1998 the International Cancer Union (UICC) demonstrated its confidence in the Norwegian Cancer Society by giving it the task of organising the UICC's 18th Cancer Conference in the year 2002 in Oslo. This World Conference has never

been arranged before in any one of the Nordic countries, and the responsibility of hosting the conference will undoubtedly give the Norwegian Cancer Society the motivation and the drive to demonstrate yet again the Society's considerable contribution to cancer-related work, both in Norway and abroad. The Norwegian Cancer Society is the first of UICC's members to decide that one per cent of the available funds shall go to

international projects within UICC's aid programme.

The good co-operation with our patients' associations has continued in 1998. People who have personal experience of what it means to have cancer will always be among our most important partners in the fight against cancer.

For further information concerning The Norwegian Cancer Society, please contact www.kreft.no

THE SWEDISH CANCER SOCIETY

CANCERFONDEN

The Swedish Cancer Society is a non-profit-making organization established to raise and distribute funds for cancer research, to provide information about cancer and to offer support to activities which, in various ways, may contribute to improvements in care and treatment. The Cancer Society – which was established in 1951 – is administered by 38 trustees representing practically the whole spectrum of organizations in Sweden.

As a non-profit-making organization, the Cancer Society receives no government grants, and is wholly dependent on donations from the people of Sweden. Via these donations, bequests and campaigns, the Society finances 75 per cent of all research projects into cancer. These projects compete nationally for degree of priority, assessed by a panel of scientific experts.

Thanks to successful fund management, the Society is every year able to distribute more funds for research than the total collected. Of the Society's annual revenue, 70 per cent goes directly to research, with the remaining 30 per cent being allocated to the Society's other activities, including prevention, information and development of care.

During 1998, more than SEK 250 million – the biggest sum yet in the Society's almost 50-year

existence – was granted to nearly 450 projects related to cancer. Also in the past year, the Cancer Society recorded a fund-raising record of just over SEK 232 million for Swedish cancer research. Most notably, revenue from bequests increased to SEK 125 million.

Financial income was somewhat lower than in the preceding year. However, the total return on managed assets was 15.7 per cent, a result that must be considered very good. The dividend from the Cancer Society's General Public Savings Fund continues to rise, and in 1998 a new financial joint venture was launched with the announcement to the public of a new unit trust fund. Over a three-year period, the venture is expected to yield SEK 25 million.

The Cancer Society supports cancer research on a broad front. The major share – 80 per cent – of the funds administered are distributed to researcher-initiated projects encompassing not only basic research projects but also epidemiological and clinical projects. The remaining portion is apportioned in the main to services at various levels, and to travel. The Society's focus on care development, patient support, general information and health information continued. Support is provided in the form, for example, of scholarships for further training to nursing staff, as well as for development projects intended to increase the quality of cancer care. For example, in 1998 support was granted for a pilot project on care in the home for leukaemia sufferers, a project that attracted considerable media attention.



The Secretaries General of NCU had a meeting in Iceland in October 1998 when they visited the Mayor of Reykjavík, Ingibjörg Sólrún Gísladóttir.

From left to right: Guðrún Agnarsdóttir from the Icelandic Cancer Society, Ninna Würtzen from the Danish Cancer Society, Ingibjörg Sólrún Gísladóttir Mayor of Reykjavík, Liisa Elovainio from the Cancer Society of Finland, Marianne af Malmberg from the Swedish Cancer Society and Lilly Christensen from the Norwegian Cancer Society.

Information from the Cancer Society ranges all the way from brochures for patients, through newsletter production, to national campaigns. For the past few years, the Society has operated its own public information helpline.

All research projects supported by the Cancer Society are described briefly in the popular science magazine *Forskning NU* (Research NOW), which also contains articles and reports on current research. The Society's newspaper *Rädda Livet* (Saving Lives) is published six times a year. Various cancer illnesses, the latest research news, care and treatment are dealt with in theme form. The Society also conducts an intensive anti-smoking campaign, for example in the form of targeted material to schools and to antenatal and child health-care clinics.

During 1998, the Society's campaigning activities were intensified. This culminated in a summer campaign encouraging more sensible exposure to the sun, *Sola sakta* (Sensible sunbathing), operated in association with Sweden's skin specialists. *Sola sakta* caravans touring the country attracted more than 10,000 visitors, and 4,000 had suspected skin changes examined. At the

same time, the message advocating more sensible exposure to the sun was carried by the media over the whole country.

In addition to press conferences, successful and prize-winning publicity campaigns, opinion-forming and participation at exhibitions, the Society's involvement in the EU's "Man and Cancer" campaign gained considerable attention, as did the new "Stop Smoking Line", a completely new venture offering telephone support for smoking cessation. In parallel, work started on persuading the country's businesses increasingly to support the work of the Cancer Society.

As before, the Swedish Cancer Society is participating in the international fight against cancer. Cross-border collaboration is continuing, via the Nordic Cancer Union (NCU), the EU's action programme against cancer and the corresponding collaboration within the ECL, the European organization of cancer societies, and the UICC, the international union of cancer societies.

For further information concerning the The Swedish Cancer Society, please contact www.cancerfonden.se

THE FAROESE CANCER SOCIETY

FØROYA FELAG MÓTI KRABBAMEINI

In March we arranged a three day course in physician-patient communication; the course was financially supported by the NCU. The tutor was Mr Anders Bonde Jensen, PhD; and there were eight participants.

In August/September we focused on “children, Sorrow and School” where Mr Per Bøge and Mr Jes Dige from the Danish Cancer Society, Cancer in Faroe with the physician Jan Dalberg and Children with Cancer with the nurse Katrina L. Joensen. Lectures were arranged round the islands as well as courses for teachers, health sisters, psychologists and educationalists and a conference in the Nordic House in Tórshavn. The attendance at all arrangements was high.

“Bót til Bata” an advisory group for women with breast cancer, held its 10-year anniversary in 1998; and in this connection special attention was paid to breast cancer. Lectures and teaching concerning breast cancer were arranged, conducted by the Danish professor Mogens Blichert Toft, of the Royal Infirmary in Copenhagen, Mr Carsten Rose, oncologist at the University Hospital in Odense, and Ms Lis Løfberg from the Company Amoena.

Together with “FÁ2”, the professional union for nurses working with cancer and AIDS patients in Faroe, “Bót til Bata” also arranged an informative campaign on breast cancer, prevention and treatment. Instruction was given in self-examination of breasts, conducted by the nurse Ms Anne Marie Kristensen. About 150 women participated.

For the anniversary of “Bót til Bata”, The Faroese Cancer Association published two booklets, one about the group, also dealing with breast cancer and what help is available, and the other one dealing with self-examination of the breasts.

Over the past two years The Faroese Cancer Association has been working on improving the services provided to people with stoma; The association has also taken steps to transfer the responsibility for providing these services to the hospitals. This transfer succeeded in May 1998 when the Main Hospital in Tórshavn established a stoma-ward. However, these patients can still contact us by phone for advice.

The Faroese Cancer Association has now got premises at the hospitals on Suðuroy (Tvøroyri) and on Borðoy (Klaksvík) for talks and advice for patients and relatives.

We are working for an introduction of mammography-screening and it seems as if the Health Authorities are willing to see this through.



Representatives from the Nordic Cancer Union visiting the Mayor of Reykjavík, Ingibjörg Sólrún Gísladóttir in October 1998.

From left to right: Jákup N. Olsen, chairman of the Faroese Cancer Society and the directors Guðrún Agnarsdóttir of the Icelandic Cancer Society and Ninna Würtzen of the Danish Cancer Society, Ingibjörg Sólrún Gísladóttir, Mayor of Reykjavík and the Secretaries General Liisa Elovainio of the Finnish Cancer Society, Marianne af Malmborg of the Swedish Cancer Society and Lilly Christensen of the Norwegian Cancer Society.

Statutes of the Nordic Cancer Union

§ 1

The Nordic Cancer Union is a cooperative body for the national cancer societies in Denmark, Finland, Iceland, Norway and Sweden.

The object of the Union is to promote the members' mutual work in their fight against cancer.

The Union is able to accept donations and, from these and other funds at the Unions disposal, can grant support for specific purposes.

§ 2

The work of the Nordic Cancer Union is administered by the Board of Directors of the Union, which consists of the Chairmen and the Secretary Generals of all the member societies, as ordinary members and the vice-chairmen as alternate members.

The Board of Directors normally meets annually, in each of the five Nordic countries in turn.

The Chairman of the Board of Directors and concurrently of the Union is the Chairman of the member society in whose country the meeting of the Board of Directors is to be held next. The change of chairman always takes place at the conclusion of the ordinary meeting of the Board of Directors.

The Board of Directors can appoint working committees if special tasks arise.

The Secretary of the Union is the Secretary General of the member society whose Chairman is Chairman of the Union. The minutes of the meeting of the Board of Directors shall be confirmed by both the outgoing chairman and the incoming chairman.

§ 3

The Chairman and the Secretary jointly, or two other members of the Board of Directors so authorised by the Board of Directors, sign on behalf of the Union.

§ 4

The Union's leadership in the country in which the annual meeting is to take place may, should it find it desirable, organise, for participants from the Nordic countries, a symposium on scientific cancer problems and/or conferences for the purpose of furthering the fight against cancer in these countries.

§ 5

The costs of meetings organised by the Union are paid in full by the cancer society in the country where the meeting concerned is held. These costs do not, however, include the cost of travel and accommodation for the participants in the meeting.

The Union's own monetary funds are administered in a separate account by the cancer society that receives the funds made available to the Union.

The Board of Directors decides how any costs not mentioned in these states shall be divided. Any such decision shall be unanimous, and shall be subject to approval by the respective cancer societies, in so far as these have to share payment of the expenses.

§ 6

In the event of the dissolution of the Nordic Cancer Union, any funds possessed by the Union shall be distributed equally among the member societies.

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