



## **Research for the future**

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The seed of what was to become the Swedish Children's Cancer Foundation was sown one evening in February 1979, when several parents got together and formed a society to campaign in favour of a separate pediatric oncology ward at the Karolinska Hospital in Stockholm. A couple of years later, a further six children's cancer societies had been set up across Sweden. In January 1982, these seven societies decided to form the Swedish Children's Cancer Foundation – a joint, national organisation for research, information, education and promotion of public awareness and understanding of the issues of childhood cancer.

The Swedish Children's Cancer Foundation's collected funds come from donations and bequests alone. Each year, about 60 million Swedish kronor (equivalent of USD 7,000,000), the majority of these funds, goes directly to cancer research. The Swedish Children's Cancer Foundation is the primary source of funding (90 per cent) for Swedish research into children's cancer, and is chiefly responsible for the success that has so far been achieved in the fight against children's cancer. The Swedish Children's Cancer Foundation has a secretariat based in Stockholm with a staff of twelve.

The children's cancer societies work directly with the ill children and their parents. This work includes providing the hospitals with toys, computer games, video films and decorating the rooms at the hospitals. The societies also arrange informal get-togethers for the parents at the wards once a week as well as other activities outside the hospitals. These activities can range from go-carting to a trip to EuroDisney in France. Most of the societies also have their own chalets, which they have either purchased or received as a donation, in their region. Parents and children may borrow these chalets at no personal expense to give them the opportunity to get away and unwind for a while. All of the societies are non-profit organisations, whose main aim is to make life easier for these children and their families. The societies also make it possible for these families to meet others in the same situation. Moreover, there are special groups for young people and those families who have suffered the death of a child.

Everyone who donates money is able to specify where they would like their contribution to go – to the societies and the children, or to the Foundation for research purposes.

### **New research committee**

In 1996, the Swedish Children's Cancer Foundation had already achieved its original goal of being able to cure three children out of every four that are diagnosed with cancer in Sweden. The vision today is that all children diagnosed with cancer will become well again. The initial goal of this vision is that by 2012 nine out of ten children in Sweden will be cured of their cancer.

“The way to accomplish this is by investing even more funds into research,” says Eva Gillström, working chairperson of the Swedish Children's Cancer Foundation. “What remain to be defeated are the most critical tumour illnesses. We are hoping that by increasing the number of research posts, we will be able to attain quicker results.”

At the beginning of 2001, a new research committee was set up – the Research Committee for Nursing Expertise including psychosocial research. The committee's main focus is on nurses, psychologists, hospital welfare officers and physiotherapists. Opinions vary greatly about how to

care for children with cancer, but many of these have no scientific basis. It is hoped that by conducting various studies and surveys, we can find out how the children themselves feel and react to the care and treatment they are given.

“Patient-based research has always been of tremendous value to the Swedish Children’s Cancer Foundation and care research is an extremely important area where children are concerned,” explains Eva Gillström. “Perhaps the new research will reveal that the children are anxious and worried about things that are totally different to what we adults believe.”

Other applications for research grants are considered, as previously, by the Research Committee for Biomedical Sciences.

Another area that the Swedish Children’s Cancer Foundation has started concentrating on in earnest is late effects. These days, two-thirds of those children that are cured of their cancer develop some form of late effect.

“To overcome this problem, we must continue our research to try and further refine the treatment methods and possibly even replace some of the medicines,” says Eva Gillström.

Children with late effects need a lot of support and understanding from those around them. In this respect, the Swedish Children’s Cancer Foundation can assist by influencing and informing the general public. Many people still believe that children who get cancer either die of the illness or, if they survive, that the lives of those children and their parents simply return to normal as soon as the child has become well again. One way of enlightening people is to work proactively by providing the public with information.

### **International research projects**

The Swedish Children’s Cancer Foundation also supports international research projects in which Swedish and foreign researchers participate. In addition to four other types of research positions, two kinds of postdoctoral positions have been made available, one of which is for Swedish researchers wishing to carry out research abroad and the other is for international researchers who wish to conduct their research in Sweden.

“We are keen to increase the number of researchers taking part in international exchanges. Scandinavia has a relatively small patient base, which means that all research takes longer. Internationally, there is a much larger patient base, which makes it possible for conclusions to be drawn quicker. In 2002, half a million Swedish kronor (equivalent of USD 58,500) was also earmarked for financing the organization of an international scientific symposium. A tremendous amount of work and effort is required to arrange such a symposium, but we hope that eventually this will become a recurrent event.

The Swedish Children’s Cancer Foundation also regularly provides the funding for conferences and seminars for all occupational groups that work with the treatment and care of childhood cancer patients, including SIOP (the International Society of Paediatric Oncology), NOBOS (Nordic meeting in Paediatric Oncology Nursing) and NOPHO (Nordic Society of Paediatric Haematology and Oncology). These days, all children in the Nordic countries receive more or less the same forms of treatment. Together, these countries have drawn up common treatment protocols, which they update at regular intervals.

In 2002, the Swedish Children’s Cancer Foundation also created two new professorships in clinical paediatric oncology in Sweden. At the moment it has not been confirmed exactly where in Sweden these will be, but discussions are underway with several universities.

### **Grants for further training**

In Sweden, the care of childhood cancer patients is concentrated at six paediatric oncology centres in different parts of the country. It is at these centres that the main care and treatment of children take place. The Swedish Children’s Cancer Foundation has allocated two and a half million kronor (equivalent of USD 292,500) in the form of educational grants for which healthcare professionals may apply. This money, which is distributed amongst all the centres, can be used by staff to attend seminars and congresses or to meet others who work in the same area and to exchange experience.

“Healthcare staff have to be given the opportunity to participate in skills development too. Paediatric oncology can be an onerous area to work in for several reasons. New developments and findings are constantly emerging at a rapid pace, and the staff need to keep updating their skills and knowledge. One way of making paediatric oncology an attractive area in which to work is to offer good opportunities for further training.”

Doctors and nurses in paediatric oncology, who work at hospitals outside the children’s cancer centres, are able to spend six months gaining practical work experience at one of the children’s cancer centres. Their salaries and associated costs are paid for by the Swedish Children’s Cancer Foundation. This opportunity enables them to develop their skills and study the latest findings and observations.

In January 2003, a new, two-year oncology training course for nurses began, funded by the Swedish Children’s Cancer Foundation. The aim of this course is to extend knowledge in paediatric oncology and paediatric oncology care.

By arranging seminars during teaching and nursing courses, for school, recreational and pre-school staff, school health service personnel and students, it is hoped to raise the level of knowledge among those groups of professionals with whom the children will mostly come into contact. Another form of skills development was also arranged for parents from the seven children’s cancer societies. A couple of parents from each ‘Visommist’ support group (‘We who have lost’) attended a two-day-long course, under the guidance of a psychologist and a hospital welfare officer, to learn how they can best respond to and help parents who have just lost their child.

### **Difficult situation for siblings**

The entire family suffers badly when a child gets cancer. Those who are particularly vulnerable are the brothers and sisters. They have to live through the trauma that comes with having an ill brother or sister and feeling that the parents do not have the same amount of time and energy for them any longer. In order to protect and help their parents, they often hide their own concern. Many brothers and sisters feel that they have no one to talk to about their situation.

The various children’s cancer societies have determined to do something about this. They arrange special weekends for siblings and many of the wards at the hospitals have nurses whose primary task is to look after the brothers and sisters.

The families can also visit the Swedish Children’s Cancer Foundation’s recreational facility ‘Almers hus’ in Varberg in southern Sweden. Parents and children are welcome to visit this facility for a week in order to relax, rest and recover their strength, as well as to meet other families in the same situation. Special mum and dad weekends are also organised here, as are courses for the healthcare staff at the various paediatric oncology centres. The Swedish Children’s Cancer Foundation pays for travel and accommodation expenses.

“The family’s financial situation often collapses when a child becomes seriously ill. A special financial group has now been set up, which will examine the possibility of principle, instead of today’s individual, assessment when it comes to care allowance. The Swedish Social Insurance Office (Försäkringskassan) pays care allowance and makes it possible for parents to stay at home with their ill child. In our opinion, all children with the same diagnosis ought to receive the same allowance no matter where they live in Sweden,” says Eva Gillström.

Furthermore, the Swedish Children’s Cancer Foundation provides assistance with legal advice in cases of a fundamental character such as financial support (equivalent of USD 2,340) on the death of a child. This assistance is very much appreciated, particularly since the costs of a funeral can come as a heavy blow in a situation where the family’s finances are already stretched to the limit after the period of illness.

## **Special handbook for parents**

This coming year will see the publication of a handbook for parents, which will be issued to all parents of children newly diagnosed with cancer. This will contain information about practically everything, from remembering to pay the bills to how parents apply for care allowance. It will include advice to relatives and friends about how they can best help the family during this period, for example by fixing meals, cleaning the house or simply being there when they are needed, phoning the family or sending a postcard now and then. There will be a long chapter with a special focus on the vulnerable situation of brothers and sisters.

The Swedish Children's Cancer Foundation also publishes books and brochures, its own magazine "Barn och Cancer" ("Children and Cancer") as well as special educational material for schools, with the title of "Min kompis har fått cancer" ("My friend has got cancer"). A guide for teachers and other school staff is also currently being produced.

"Our website, which has a constantly increasing number of visitors, is another excellent source of information. This spring will see the publication of a brand-new, up-to-date book called "Cancer hos barn och ungdomar" ("Children and young people with cancer"). This book describes all the diagnoses and treatment strategies in a straight-forward, easy-to-grasp manner. Due to the late progress in cancer therapy, such a book has been truly needed for a long time. Each family will receive a copy of this book as soon as they are first informed of their child's illness. It contains many of the answers to the questions and thoughts that arise once the initial shock has worn off.

In recent years, the Swedish Children's Cancer Foundation has worked actively with major campaigns by means of outdoor advertising and television spots. The aim has been to reach the general public and get the message across that three out of four children are cured of their cancer these days.

"In terms of fund raising, this has generated excellent results. Everyone who gives a contribution receives a letter of thanks along with information about what the funds are used for. Our campaigns have been designed to ensure that the people who support us with contributions get to know more about us afterwards. We also influence public opinion by actively working with the mass media. This is done by means of direct contacts, press releases and seminars for journalists. Since the Foundation does not receive any form of governmental support or subsidy, but depends entirely on donations and bequests, its credibility is totally crucial for our work in the future," concludes Eva Gillström.

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