

News from the editors

SIOP Asia-meeting

Ever since Prof. Arya from the All Indian Institute of Medical Sciences in Delhi (India) got in contact with the international parent work at the Frankfurt-meeting (in 1998), it was his desire to initiate parents' activities in India and to invite parents from all over India to a conference similar to the ICCCPPO-meetings.

The second SIOP-Asia conference held in November 2002 in Delhi was such an opportunity. It was the first pediatric oncology conference in India that included a very extensive parent program. Parents from all over Asia were invited to join and share their experiences. Four delegates of ICCCPPO were involved in desinging the program and chairing the meetings together with representatives of Sahayta from Chandigarh. It became to be a very interesting two days of intensive work, talks, reports, presentations, workgroups, round table discussions – and not to forget social events.

We learned a lot from our Indian hosts, most important for us was to understand that many issues which are "normal" in our surroundings are viewed totally different in the Indian context. Here, we were told, cancer is still considered to be a stigma, especially cancer in children. Often families fear to talk about their children even though they survived the disease as they may be cut off from social interaction and their children may be considered not fit to be married. A young woman, a survivor of a Hodgkin's disease, broke into tears while reporting about her disease. She was sure that she will never find a husband after what she had been through.

We heard about the work of many courageous groups such as Sahayta and others who support



families in need, or bereavement, counselling individuals and groups and providing palliative care. We learned that survival rates (especially in leukemias) have increased considerably, that is why the theme of the conference was "Childhood cancer is curable". We tried to support the positive aspects and assured those still hesitant to keep on in their wonderful and rewarding work.

The next SIOP Asia meeting in Bangladesh will again include a parents' program (s. announcements).

Survivors meeting

This newsletter issue reports about the new tradition of including survivors meetings along with the annual ICCCPPO meetings. For the first time we will send the newsletter to all addresses of survivors known to us – thus giving them a possibility to be included in the international network. Should you know of any person in your group interested in receiving the newsletter regularly, please inform us about his/her address. There will also be a special section on the website designated for survivors issues.

ICCCPO AGA-meeting 2003

Due to the ongoing war in Iraq the ICCCPPO board decided at its most recent meeting to seek a venue other than Cairo for this year's AGA meeting. It decided to accept the offer from the Barretstown Camp in Ireland to use their facilities for this meeting as well as the survivors meeting, which will take place at the same time. Please note that this will mean a change of dates: Oct. 2-5, 2003 (instead of Oct. 6-8)! All news about the registration and program will be found on the website as soon as arrangements have been made: www.icccpo.org.

International Childhood Cancer Day

Was celebrated on February 15 with great success in many countries. We will report more specifically about this event in the next newsletter.

*Gerlind Bode
For the editorial board*

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Presentation at the Siblings' Session of the SIOP- Asia Conference in Delhi, November 2002

I never imagined that such things could happen to my own sister!

What I share with you today is an account of my personal experience of seeing my younger sister go through the trauma of cancer. Before I begin, I, Kanika, thank Sahayata and ICCCP0 for giving me this opportunity to reach out to other families in similar situations.

We have a small family of 4- i.e.. me, my parents and my sister Nitya, who is 7 years younger to me. I remember how excited I was when she was born. Being an only child, I used to feel rather lonely and really looked forward to having a sister. So, when she finally arrived, I adored her like my little treasure!

When she was just 12 days old, she was diagnosed with meningitis. For me, it was heart-rending to see that innocent young thing being mercilessly pricked all over. She recovered soon, but when she was just a month old, she started having convulsions with high fever. She kept falling ill frequently, but we thought, as she grew up, health would stabilize.

But little did we know, that the worst was yet to come... When Nitya was about 7 years, she started complaining of a severe pain under her right knee. Initially, it was treated lightly, but when the pain persisted too long, an investigative surgery was performed to reveal the most horrifying news, on 3rd Aug 1977, that she had cancer-what they termed as Acute lymphoblastic leukaemia (ALL)

I was 14 years old at that time and just knew that Nitya had been hospitalized for some knee surgery and would be back soon. While my parents were in the hospital, I was left with my grandparents with whom I used to visit my sister every evening.

But I remember, one evening, when we reached home, everything was suddenly very different. Mummy was crying silently and Papa was nowhere to be seen. There were relatives all around with a serious look on their face and they would keep coming to me, hug me and say, "everything will be fine, you don't worry, take care".

I sensed that something was seriously wrong, but I was just too scared to ask!

After that evening, things started changing rapidly. Whenever we went to the hospital, Mummy and Papa were always in a tense flurry and I never got a chance to ask them anything. I distinctly remember that strange and left-out feeling I got in those days. When I demanded to know what was going on, I was merely told: "Nitya will be fine soon. Don't worry, sab thik ho jayega". Somehow, I was not convinced, but I asked no further...

I resigned myself to the fact that my parents would have no time for me now and that I had to take care of myself. In this process, I got to be pretty independent.

I started thinking of how to entertain my little sister while she was in hospital, so that my parents got a little break. I would take small gifts, toys and books to cheer her up and sometimes we would talk for hours, when she told me about her difficult day. Other times, she would be irritable due to the nausea etc. I remember doing all sorts of things to amuse her! She would specially call for me when she felt sick and I would feel rather important!





When she came back home after 5 weeks of hospitalization, I was very excited because her homecoming was at least one step of life returning back to normality. Now, I could spend more time with her and after coming back from school, we used to spend entire evenings reading books, playing games and singing songs. Sometimes, she would wake up in the middle of the night feeling uneasy, and I remember playing and amusing her all night!

Now, even though I adjusted to this new routine, at times I felt exasperated because it would take away my entire evening and that began to affect my studies too! It was getting difficult for me to manage everything smoothly and I grew irritable at times, because all this just didn't seem to have an end.

Unable to contain myself any longer, I asked my father directly what the matter was and he told me the harsh reality that she had cancer! I got quite a rude shock that day because I never imagined that such a thing could happen to my very own sister! The thought of how close I was to losing her suddenly filled me with love and possessiveness for her I thought how much more concerned and understand-



ing I would have been, if I had known this all along. I was also filled with a new respect and awe for my parents for the way they were handling everything with such courage and perseverance. I got more responsible

and assured them that I would manage my studies well and they need not feel guilty for not being able to spend time with me.

In this way, the days rolled on.....

During the treatment the role of the doctors was very important. Dr Arya, Dr. Yogesh Jain and Dr. Sunil Gupta were all a source of constant support and encouragement.

In the hospital, I also come across Mrs. Ohri and Mrs. Harmala Gupta from Cancer Sahyog. I was touched by their small gestures to cheer up young patients and even I felt like doing something similar.

Finally, after the long treatment was over, Nitya regained her health and resumed school. We moved to Chandigarh, where I happened to meet Mrs. Bhan in PGI hospital during one of Nitya's check-ups. She told me that she is a part of Sahayata- a support group that works to provide emotional and financial support to cancer patients. I was impressed by their care and concern, so when she invited me to join them, I eagerly did. Mrs. Tuli, the President and other volunteers warmly welcomed me into the group.

Since then, I have been involved in their efforts of raising funds for poor patients by getting donations, sponsorships and selling greetings cards made by cancer patients. I have also led awareness drives and rallies to spread information about cancer and it's treatment, while other volunteers personally spend time with patients and their families.

As a sibling, having seen through Nitya's treatment so closely, I can easily relate to the necessity of all this comfort and guidance in these crucial times.

I would like to say a lot more about Sahayata, Sahyog, our doctors, my relationship w/t Nitya and so on, but time doesn't permit and I'll just wind up with a note for other siblings...

That when your brother/sister is diagnosed with cancer and is jolted away from normal life , it is a time when they need you the most, because the love and friendship you can offer them, cannot be substituted by anyone else; not even your parents.

The unique bond that I developed with Nitya that time, by just being there with her, is something that will continue forever and something that we are both proud of !

Kanika Mohan



2nd SIOP - ASIA CONFERENCE



SIOP-ASIA CONFERENCE IN DELHI

Maura McKernan

I began writing my story of childhood cancer at age six and continue adding little bits as I am moving though life ...

Report of a childhood cancer survivor

September 1985 was when I started to show symptoms of my illness. Throwing up in the early part of the day was typical for me, and included the embarrassment of throwing up at school in front of my classmates. Headaches then followed, and I started to transform from a happy-go-lucky child to one who was sad and irritable. It took months of going to doctor's before I was diagnosed with my real illness.

On December 22, 1985 I was taken to the Alberta Children's Hospital and on December 23, I was diagnosed with a cancerous brain tumor called Medulloblastoma. It was a large tumor, and I was very ill. At the time my family was told that I only had a 15 – 30% chance of survival.

I was able to go home for Christmas Eve and Christmas Day, but by that time I had developed bleary vision and dizziness. Christmas Day I fell into the cupboard that resulted in me being rushed back to the hospital to have emergency surgery at 1:00pm Christmas day. Following surgery I contracted meningitis, which added to the stress my family and I were already under.

With a total of 5 surgeries, radiation treatment, CAT scans, spinal taps, myelograms, blood transfusions, tests for HIV and hepatitis (negative results), the loss of a beautiful head of thick black hair (which never grew back in some spots and only very fine and thin in others), I survived.

After Effects

Although it has been many years since my illness and treatment, I have life-long effects from the treatment I received that saved my life.

These mental and physical scars will stay with me for the rest of my life. My height and growth were affected greatly by the amount of radiation treatment I received.

I have scars as well as nerve damage on my right side of my body due to the surgery I received. This affects my balance, coordination and motor skills. The surgeries I received were performed before screening for AIDS and hepatitis had begun. My thought patterns and speed are slightly delayed. The results of these limitations showed in my writing, motor and coordination skills in some activities. These as well as other side effects made school a terrifying, struggle and an atmosphere full of anxiety.

I believe that my long hospital stay deprived me of developing the majority of my social skills. Therefore,

throughout all my school years I was extremely lonely, edgy, anxious, sad and at times angry. But gradually my life is branching out to a beautiful successful one. I am learning to release what I have bottled up for years. Throughout my years of remission and reaching the stage of being cured, my many life-challenges and experiences, I am learning so much about myself. I have discovered and am continuing to discover that my gifts and strengths I hold with me are the gifts of gentleness and reliability, I am also a very sensitive person, I am proud of who I am.

Presently I am going to College in Calgary, and my goal there is to become licensed to work in the field of health and wellness. I am a passionate person who has a gift of working with people, and I am continuing to develop my skills so that I can gain the strength and knowledge to be the best person I can be, for my self, and so I can share all that I have with others. I take pride in what I do. What I do provides me with meaning, happiness and enthusiasm for living life to its fullest.

My experience with cancer has taught me that kids who go through this torturous disease come out as much stronger people. Although a significant proportion of their lives have been taken away from them, they always find ways to deal with their struggles and difficulties without ever giving up due to the strong will, determination, motivation and effort these kids have.

Sometimes interaction with peers is difficult while interacting with adults is much easier, due to the amount of time spent around adults (doctors/nurses) etc, and the lack of interaction with other kids their age. Because of the amount of trauma that these children face, they are forced to grow up faster than most kids.

If I were given the choice to go back in time and change or erase the fact that I had cancer, I WOULD NOT! I believe that I was given the challenge of battling cancer for a reason! I believe that I have and am continuously being given so many different learning opportunities, experiences and responsibilities because I was given the gift to have the will and strength to battle this disease. I believe that I am a much stronger, and a more knowledgeable and determined person because of the challenge I was given. I believe that I have a lot to share with others, especially those who are in the midst of battling cancer and their parents, families and friends.

Finally, it is also my belief that the fullest way to live life is to include some type of spirituality. Our thoughts create our experience. The way I see it, God gives us challenges he knows we can handle no matter how difficult. Everything happens for a reason.

I began writing my story of childhood cancer (age six) in 1996 and continued adding little bits as I have moved through my life.

Maura McKernan

Mark Chesler, with the assistance of local survivors

Support and advocacy groups for survivors of childhood cancer

As more young people survive cancer it is increasingly common for them to seek other survivors like themselves. In more or less organized groups survivors compare their experiences and coping patterns, find support for their life choices, participate in social and recreational activities, and begin to advocate for change in medical and social services. Many play an important role in the medical system or in parent groups, meeting and talking with newly diagnosed children and families. These young people are a tremendous resource in the worldwide fight against cancer and in the effort to improve the quality of life of patients and survivors.

Recent research indicates that many survivors of childhood cancer would like to meet and talk with other survivors. ICCCPPO seeks to serve this need and to learn from survivors' experience and wisdom by helping to organize survivor conferences at its Annual General Assemblies. At these meetings, groups of survivors from different countries meet with one another, talk with experts, and share their ideas and concerns with parents. ICCCPPO also is trying to support and strengthen the development of survivor groups in other countries which have not yet established such programs.

At the 2002 meetings in Porto we asked representatives of several national survivor groups to create reports of what they did in their own countries. Following are some examples and excerpts from these reports. IF YOU HAVE STORIES OF WHAT SURVIVOR GROUPS ARE DOING IN YOUR COUNTRY OR CITY PLEASE SEND THEM TO US.

United Kingdom: TOPS

(Teenage Oncology Patient Support):

TOPS was set up for teenagers and young people between the ages of 12-25 who have or have had cancer or leukaemia. TOPS was founded in 1993 by a group of oncology nurses at Bristol Children's Hospital. It is now part of the existing cancer charity, CLIC (Cancer and Leukaemia In Childhood). The aim of the group is to provide both social and emotional support for young cancer sufferers.

TOPS is mainly based in Southwest England and is completely free of charge to all its members. With the help of many doctors, nurses and volunteers the organisation provides a wide variety of different events throughout the year, including art and music weekends, bowling and cinema trips, as well as the annual summer holiday in South Wales. The week's holiday enables both able and disabled bodied members to work together to participate in many fun and rewarding activities, such as archery, canoeing and climbing and also provides a valuable support network within the group. In addition, the holiday provides a peaceful environment allowing members to escape from the fears and anxieties of hospital treatment and to relax in the company of others who share similar experiences.

TOPS also provides a quarterly newsletter that is distributed to all its members and therefore, allows those who are unable to attend the various organised trips to continue to be included in the group.

The newsletter contains a number of reports concerning past and future events, profiles on members, as well as photos, poems and puzzles.

There is also a TOPS pen pal list, which includes the names, addresses and email addresses of those members who wish to be part of the rapidly expanding network of support. Members find the pen pal list very important for keeping in touch with each other and maintaining close friendships.

TOPS hopes to provide communication, support and life long friendships for all its members.

[By Tracey Chorley, Alex Brownsdon and Byrony Carr]

Germany:

Twice a year there is a weekend meeting in Bonn for young people with cancer. Forty to fifty young people from all parts of Germany come there. At these meetings they exchange experiences and have fun together. Informational lectures are given by doctors, psychologists and patients. On Saturday there are workshops on different subjects, as well as arts, sports or conversation groups. In the evening there are parties with music and dancing. These meetings are very useful because they help build common bonds and a community spirit among survivors..

Each year, the German Kinderkrebsstiftung (Children Cancer Aid Society) organizes a week-long biking tour (die Regenbogenfahrt or Rainbow tour) for approximately 20 former patients, who bike through different parts of Germany to visit pediatric oncology centres. The bikers try to encourage the young patients on the wards by demonstrating that life can be very active and rewarding again after such a terrible illness.

A magazine, "TOTAL NORMAL" summarizes the content of the Bonn-meetings, includes contributions by former patients as well as medical news and articles of general interest.

[By Ruth Langenbach]

Netherlands:

The Dutch Youth Support Group BRUS:

Ten years ago, in 1992, the Dutch support group BRUS was established. Unlike other support groups, BRUS wasn't just meant for survivors of childhood cancer: siblings, children still in treatment and children from whom a brother or sister had passed away, also are involved. Although people's personal circumstances differ, the age range in the group is from 12 to 35. Despite these differences, the group works well and many fine friendships build up between survivors and siblings of all ages. Since the day it was founded the group has played an important role in the parents' organization (VOKK). The VOKK itself has become very active over the past 15 years in producing books, brochures and other materials on the subject of childhood cancer, and helping to organize parent support groups and symposia. Its goal is to help parents who are in the difficult situation of having a child with cancer and to inform the broader public about this subject.

Every year at least two general VOKK meetings are held. During those meetings the BRUS support group discusses subjects young survivors think about and/or struggle with, such as guilt, problems in school and relationships with peers and parents. In addition, every year a weekend-camp is organized. From Friday night until Sunday afternoon a mixture of activities is offered: horse riding, walking by the sea, nightly dances and parties and early morning group discussions. Some senior group members usually volunteer to guide these weekend sessions. The number of participants has fluctuated between 25 and 45. At the weekend camps, or during VOKK meetings, people who wish to be in one-to-one contact with one another can exchange telephone numbers and establish closer contact. People very often meet each other during one of these and personally exchange addresses and stay in touch. Friendships such as those turn out to be very important. Other organizations sometimes invite the survivor group to join their activities: in that way a trip in some (50) sports-cars to the Dutch racing circuit was arranged.

For three years a quarterly magazine for young people living with cancer has been published. 'Lef' is read eagerly by its members and is also spread in hospitals treating children with cancer. Each edition is on a specific topic, trying to offer different views on a problem. BRUS and VOKK meetings and activities also are reported in this magazine. The purpose is to inform people who were not able to participate about what occurred (and how much fun it was).

[By Eva Coenen]

Greece- "FLOGA":

Survivors hold regular meetings at the office of the parent organization (FLOGA). There people exchange information and share experiences, suffering and concerns. In addition, they attend and participate in medical seminars/lectures in order to gain up-to-date information about childhood cancer issues. Many survivors also help in the preparation of presents for children who come to parties for children who are in the hospitals during Christmas and Easter. Some survivors also make visits in departments of some hospitals. There they talk with patients and cheer them up by drawing, reading, playing etc.

Many siblings also take part in these meetings and activities.

In the future survivors in Greece would like to publish a magazine or newspaper with medical news, interviews, and stories about individual survivors. In addition, they wish to translate medical articles into language that might be useful for survivors and for children in therapy and parents. These materials could be distributed in hospitals and sent to members of the FLOGA association. Working with FLOGA, survivors hope to help with the operation of the new "House of the Children of Floga" – a building with 23 rooms for families from provinces whose children must have their therapy in hospitals of Athens.

[By Emily Tsirou]

Portugal:

In Portugal the survivors' group is called "The Barnabe's Group", a group of young children and teenagers with cancer, some of whom are off-treatment, some cured, and some still on treatment. They have meetings in which they share their life experiences with other young people with cancer. This activity, called Barnabé Volunteers, is a program of support for children and teenagers provided by former young patients. Survivors also engage in a lot of social and recreational activities, including holiday camping, rafting, canoeing, rappelling, attending soccer games and circuses.

The survivors group also works closely with Acreditar, the Portuguese association of parents and friends of children suffering from cancer. Together with Acreditar, special programs for survivors and children being treated for cancer include: The Barnabé Book – a coloring book enabling children to under-

stand the treatment process by way of a story; The Teenagers Book – a diary of feelings and emotions written for the teenager; Gaspar Químio – a cartoon storybook explaining the chemotherapy process and its purpose; Rui Rádio – a cartoon storybook explaining

explaining radiotherapy and its purpose; and regular camps, weekend camps, day trips and various activities for children undergoing treatment.

*[By Madalena D'Orey and Patricia Goncalves]
For regular news on survivors issues
visit the ICCCPPO website: www.ICCCPO.org*

Guidelines to support education for children with cancer

1. When diagnosed with childhood cancer

The meaning of education

Difficult treatments and long-term hospitalisation sometimes cause developmental and psychological problems for children. Children tend to undergo anxiety that they might be left behind academically and socially, and have no chances to improve their social skills because of their limited experiences. It is education that can solve these problems.

Education for hospitalised children has three important and special meanings:

- Education will help children keep up with school studies. Many hospitalised children are behind in school studies because of their frequent absence. In-hospital schools can provide individual instruction according to the children's particular needs.
- Education will support children psychologically and empower them to fight against their diseases. Education can provide children with «I can do it» experience and enhance their self-esteem and self-confidence. It can even foster a feeling of self-control over their physical conditions.
- Education can also encourage children's psychosocial development. Teachers will arrange many programs, which will broaden children's experiences and increase their social skills.

Therefore, education is a key to improve QOL of hospitalised children.

Communication with the regular school at the beginning of the hospitalisation

Keeping in touch with the homeroom teachers and classmates at the regular schools will psychologically support children undergoing painful treatment. In order to maintain a good relationship among children, parents and the regular schools, the proper initial action should be taken. Firstly, parents do not have to explain everything about the child's condition to the school. Parents can simply tell the school about the necessity of the hospitalisation and temporary absence from school. Later, when things have settled down, the school can be provided with further information. At that time, priority should be given to the will of the sick child. What information is told to the school should be discussed among children, parents and medical staff. It would be best if parents arrange a meeting between schoolteacher and medical staff.

Opportunities to study in the hospital

At the beginning of a period of hospitalisation, medical staff must explain the importance of receiving education even while in the hospital. Education for children during hospitalisation is provided in one of the following places:

- At a special school for the health-impaired adjacent to a hospital
- In a classroom that a neighbouring elementary or junior high school has opened in a hospital
- In a visiting class by a teachers dispatched from a special school for the handicapped

If children want to attend an in-hospital school, they have to go through the formal process of transferring from their regular schools. If children are diagnosed with cancer, parents should visit the regular school or the counselling service of the local board of education to consult about education during hospitalisation. If there is no in-hospital school, parents can ask the local board of education to open a new in-hospital school with the help of the medical staff.

How children's homeroom teachers provide support

Children's strong desire to go back to their regular schools enables them to fight against cancer and retain control of themselves during painful medical treatments. Therefore, homeroom teachers play an important role in supporting children. Acquiring necessary information, they should understand what the children and parents want the school to do and promote co-operation among other teachers for the children. Paying careful attention to the children's privacy, homeroom teachers should give proper information to the classmates and their parents and discuss how they can support the children. Teachers should keep in mind that the children are still members of their class even though they are in the hospital and don't come to class.

Relationships with parents of classmates

Parents of children with cancer sometimes feel awkward about getting along with parents of other children as they did before the diagnosis. They may be obsessed with the « Why only my child? » question and feel isolated from other parents. If the situation permits, parents need to be open to communicating with

others and try to acquire understanding and support from them. Asking for help is the first step in building good co-operative relationships around children with cancer.

Communication between the regular school and the in-hospital school

Many hospitalised children are behind with their school studies because of frequent absences. In-hospital teachers need to collect necessary information from the regular school in order to identify the individual needs of the children. Speaking with the regular school from time to time, in-hospital teachers can build a bridge between the hospitalised children and the regular school.

Care for siblings

Brothers and sisters of children with cancer often feel lonely because their parents spend a lot of time at the hospital. Sometimes their loneliness and anxiety cause emotional problems. Many siblings may understand the situation. As they will also be very worried about their sick siblings, it is essential to properly inform the siblings of their diseases. Parents should ask medical staff and schoolteachers (or day care workers) to pay careful attention to the siblings. It is necessary to form a support network for the siblings as well.

2. School education during hospitalisation (after treatment starts)

School education in the hospital

The contents of the education at in-hospital schools are basically the same as those at regular schools. If children are unable to go to the in-hospital school, a teacher will directly visit the children and teach them at their bedside. Studying develops a sense of self-efficiency in children and school activities will enhance the children's motivation to fight against their diseases. Teachers at in-hospital schools should provide them with individual and flexible educational programs according to their particular needs, and give opportunities to try various activities, such as work-study and collaborative work, within the restricted conditions. Teachers need to pay special attention to the children's psychology as well as physical conditions. Needless to say, collaborative work with medical staff and other support resources is essential for teachers.

Relationship among the patients

Hospitalisation separates children from their families and throws them into the «small world» of the hospital. Usually hospitalised children are strangers to each other. The in-hospital school should provide children with the opportunity to make friends with each other. Children will share their interests, hopes for the future, and sometimes share and console each other in their anxieties and pains. Through such peer relationships,

children develop their social skills. However, sometimes children exchange incorrect information, which may increase children's anxieties. Special attention should be paid to the relationships among children.

Communication with the classmates of the regular school

It is not an exaggeration to say that friends can be the strongest support resource to empower the hospitalised children. Before informing the classmates about children's diseases, the teacher should ask the child and its parents what it should be told and how. If the classmates want to visit the children at the hospital, they should ask in advance if it is okay with the children's parents. If the children have alopecia or medical scars, or when the children are not informed about their own diseases, classmates' visits are sometimes unacceptable. However, letters, emails and taped and video messages are always welcome and cheer up the children. It is important to consider the children's physical and mental conditions. The teachers should continue to send or bring class newsletters, which will please the children more than teachers can expect. When a class shuffle takes place, special consideration for the children is required.

Children who cannot attend in-hospital schools

If there is no in-hospital school, the regular schoolteacher is expected to carry out more essential functions to support the children. They should make individual education programs for them and remember to be the key connection between the children in the hospital and their support resources at the regular schools. It is desirable for teachers to visit the children in the hospital as often as possible and the regular school should back up the teachers' visiting hospitals.

3. When returning to regular schools

Communication between schools and families

A successful return to school is one of the highest hurdles for children with cancer. They feel anxiety that they can not keep up with others or that classmates will not except them as before. School staff may also be confused about accepting them. Parents and school staff should exchange as much information as possible, including the doctor's advice. It is beneficial if parents, school staff and medical staff can have a joint meeting. At that time, children's participation is desirable. Schools should understand that the children tire easy and are extremely sensitive to viruses, or that they may sometimes be late for school or leave school early for medical care at hospitals. The homeroom teacher should give a talk about the children to their classmates in advance of their coming back to school. Especially if the children have changed in their appearances, the teachers should explain the reasons and develop sympathetic understanding of the children. People around the children can not exert too much effort to support the children's smooth return.

What an in-hospital teacher should prepare for the regular school teacher

It is important for the in-hospital teacher to pass a written record, which clearly describes what the children have studied, their interests, and their motivational level, to the regular school. The information will make it easier for the regular schoolteacher to understand the children's school life in-hospital. In case children can not attend regular school immediately after hospital discharge, both teachers should make a special educational plan for them, such as sending study material for studying at home. The most important thing is, to never leave any gaps in school studies.

Co-operation between regular school teachers, in-hospital school teachers and medical staff

It is important for medical staff and the in-hospital schoolteacher to closely co-operate with the regular schoolteachers, respecting each other's expertise. Especially when leaving the hospital, children have to go through great changes and need well-organised support. The in-hospital schoolteachers should take responsibility for building bridges among the medical staff, the parents and the regular schoolteachers.

Life after returning to regular schools

Heartfelt sympathy and support shown by teachers and friends encourages children to overcome their handicap. Setting personal goals and joining enjoyable activities are also effective in enhancing children's motivation. Some children are sometimes teased or bullied about the change in their appearance. Paying careful attention to their mental and physical condition, teachers should plan activities that allow the same participation as others, as long as the activities are not too hard for them. Teachers must not freely pass on to others information related to the children's diseases that should be kept secret.

Relationship with other children's parents at the regular school

Support from the classmates' parents is necessary for the children's smooth comeback. Some parents of children with cancer may hesitate to communicate with other parents. Sharing information about their child's disease can help to avoid misunderstandings of other parents, and help to prevent prejudice against a sick child.

Care for siblings

Siblings may face being teased about their sibling's diseases. In advance, the parents should talk to both the children and the siblings about how to deal with other children in difficult situations. If the siblings know what information has been given to the classmates, it will be easier for them to manage when problems occur. Parents may have a tendency to focus on the sick children who have just returned home and are starting school again. However, it is also important for them to pay adequate attention to the siblings. If

necessary, medical staff and teachers should respectfully remind parents of this.

4. Education for children who need special attention after treatment

Children who need special attention after treatment

In some cases, it is still necessary to surgically remove or amputate a child's body part. It is often the case with children who underwent radiation exposure or chemotherapy that they suffer from some kind of disorder after the treatment. Schoolteachers tend to be so afraid of accidents that they may restrict such children's activities. Children with disorders want to be treated in the same way as others. The best possible education should be individually planned according to the advice of medical staff. The educational environment should allow children to develop their abilities to the highest degree.

Children who need mental support

Some children who have recovered from cancer say, "I had more problems after the treatment than during treatment". During hospitalisation the children are constantly surrounded by supportive people, but after the children leave the hospital and return to their regular schools, people around the child do not always thoroughly understand the child's situation. Especially adolescent children need support resources. They should be informed of the fact that hospital social workers, paediatricians, and the "Children's Cancer Association of Japan" are always available to assist in any way they can.

5. Education for terminal cancer children

Unfortunately, there are children who still cannot be cured, and education has an enormous role to play for these children. When it becomes evident that the child is in the terminal stage, education providers can participate in making the children's remaining days as good as possible. Care for the sibling is also indispensable.

6. Conclusion

We would like to emphasise how important the making of a good collaborate system around the children is, and how much education can empower children with cancer during hospitalisation. Even when they are in the hospital with cancer, they are children and growing and developing, and need education. We really hope every child hospitalised with cancer will have the opportunity to be educated, and that no handicaps will be caused by the experience of being hospitalised.

We hope that all people involved will continue to discuss and exchange ideas. We hope that our guidelines will be modified and improved, and we hope that many people will read and make use of these guidelines.

We, as adults, should recognise and teach children how precious and fragile human life is and how important it is for us to support each other.

The Children's Cancer Association of Japan, established in 1968 by some bereaved parents, is a support organisation for children with cancer and their families. At present, we have 14 branches in the country, and there are about 4000 members (of those members 92% are patients and their family, and 8% are medical staff).

Our activities are:

- Providing counselling services by professional doctors and social workers
- Conducting self help groups sessions for long term survivors (Fellow Tomorrow) and grieving parents
- Co-ordinating volunteers for tutoring and playing with children in the hospital
- Providing financial and emotional support for families and research projects related to paediatric cancer

- Publishing newsletters (quarterly)
- Registration of paediatric cancer cases; CCAJ has been in charge of this program since the foundation of this association. The number of cases are reported from 6 local divisions to headquarter (Tokyo)
- Co-ordinating our 14 branches, including local programs
- Supporting summer camp for children with cancer currently under treatment and/or survivors with true diagnosis
- Managing three residential houses for parents
- Membership application is always available.

Children's Cancer Association of Japan
 6-24-4 Kameido Kota-ku
 Tokyo 1360071 Japan
 Tel. :+81 3 3638 6551
 Fax :+81 3 3638 6553
 e-mail : nozomi@ccaj-found.or.jp
<http://www.ccja-found.or.jp/>

Back to School Kit

A Back to School Kit designed to help children with cancer ease their way back into the school environment has been introduced in Canada. The kit contains four cases of materials aimed at children in the following age groupings 5-7, 8-10, 11-13 and 14+. Each contains books, videos and interactive games that explain childhood cancer, its effects and how others can help the patient. Classrooms can keep the kits for one month. The kits are distributed by oncology nurses, social workers and/or community liaisons to schools in their area and many of these will also speak to the class and teachers to introduce the resources and help facilitate discussion in the classroom.

"We have collaborated with many oncology professionals who are already running school re-entry programs in their local areas. Our program is a great hit with many of them as they now have resources they can leave with the class after their visit and the students and teachers will have time to process the materials," said Karen Herder who is responsible for establishing the contacts across Canada.

The idea behind the kits came from a similar program initiated by the Dutch childhood cancer organisation Vereniging 'Ouders, Kinder en Kanker' (VOKK)

proving that sharing good ideas can be of benefit worldwide. For more information contact Karen Herder, Program Coordinator Email: kherder@candlelighters.ca or visit www.candlelighters.ca

New books aimed at children with cancer

Candlelighters in America have recently added two new books to their resources collection, aimed at children diagnosed with cancer. The first, **Chemo, Crazyness and Comfort, My book about Childhood Cancer** is by Nancy Keene and is aimed at children between 6 and 12 years of age. It is an easy to understand, comprehensive guide including a journal section at the back and pages for pictures and questions to be used by the child at the end of each chapter.

The second book, available in both English and Spanish, is **The Amazing Hannah, Look at Everything I Can Do!** This 28 page picture book covers all aspects of treatment as seen through the eyes of a preschool child being treated for cancer. Both books can be ordered from Candlelighters America www.candlelighters.org Email: info@candlelighters.org

This article was reprinted with permission from the CONTACT magazine (Spring issue No.18, 2003), the magazine of UKCCSG and NACCCPO, www.ukccsg.org/contact_magazine.htm

School shouldn't be a bad memory

Children with brain tumours often face more complex difficulties in returning to school than children with other tumours as Education Consultant Beth Wicks explains

Implications for the Future Education of Children with Brain Tumours:

"The child's return to school is not the end point of rehabilitation. Rather school is an extension of the rehabilitation process begun in hospital..." (Larkin, 1992)

Any cancer and its treatment can obviously affect a child's access to education and academic potential, as a result of both the physical and emotional consequences. However, there is an added complication for children with brain tumours. The existence of the tumour, plus the effects of therapy or surgery can cause an acquired brain injury (ABI). The difficulties these children may subsequently face are, therefore, similar to those encountered after other injuries or illnesses that cause ABI.

Such an injury can provoke special educational needs that may be complex and different from other learning difficulties with which teachers are familiar. There are a number of reasons for this:

Until that time the child's cognitive and neurological development was, in most cases, normal.

Characteristically, the pattern of difficulties is "patchy". The child retains previous knowledge and some areas of current skills are preserved but with an overlay of acquired difficulties.

An ABI can affect future neurological and cognitive development (which continues throughout the first two decades of life).

When a child returns to school the physical and medical problems he may face are often recognised and addressed. Learning difficulties as a result of the injury, rather than absence from school or anxiety, may not be particularly apparent at that time. Problems in areas such as concentration, organisation or memory skills may well be attributed to those other factors. Any emotional difficulties can be exacerbated by the child's awareness that he cannot complete academic tasks or engage in social communication in the way he did previously. Frequently, the possibility of acquired cognitive problems is never raised with the child, family or school.

Some children, particularly young children, cope well when they initially return to school, but encounter problems years later. This is as a result of the fact that the pace and demands of the school cur-

riculum increase and damage may have affected areas of the brain controlling particular skills that develop as the child matures. It is only at the time when this would normally happen that the difficulty becomes obvious.

Unfortunately, the majority of teachers and educational psychologists have no training or information regarding ABI and, therefore, the specific difficulties facing these children are frequently missed or misunderstood. As the child's previous learning is often intact, his difficulties may be initially masked and are more likely to affect his ability to acquire new learning in the future. Sometimes the problems are superficially subtle, but can have very significant effects on the child's academic progress and potential and therefore on his self-confidence and self-esteem.

Without appropriate understanding and provision a child's difficulties can escalate. Ongoing monitoring is vital, even if initial difficulties are not apparent. Appropriate intervention is often simple, but requires understanding as the needs of these children differ from others with learning difficulties. Teachers may say that these children do not require any additional or different assistance because there are many others in the school whose academic performance is less good. The only relevant comparison for these children is with their previous and present potential, not with other children.

Education is a crucial part of continuing rehabilitation. Appropriate provision enables maximum curricular access and achievement and helps in rehabilitation of, and compensation for, acquired deficits.

In order that these children's needs are appropriately met we must ensure that:

- families and education personnel have appropriate information
- there are efficient links between health and education services so that these children's needs are highlighted
- there is a partnership with parents when planning provision

Although it may require additional funding, it would be of considerable benefit to these children and others with ABI if appropriate guidelines were produced with recommendations for long term provision and monitoring to include both health and education services.

Beth Wicks

This article was reprinted with the kind permission of CONTACT magazine, the magazine of UKCCSG and NACCPO (Spring issue No. 18, 20035)

Dr. E. Michiels

Palliative home care for children in Antwerp.

When a child is diagnosed with cancer, everything possible will be done to achieve curation. Unfortunately, for a number of patients at some point there will be no curative options left, and treatment has to switch to palliative care. The same dismal prognosis is seen in some children with metabolic or neurodegenerative disorders.

The growing interest and possibilities in palliative home care for adults has luckily made people realise that also children (and their parents) wish to spend the last weeks or months of their lives in the comfort of their own homes and families. Even more than for adults, a hospital appears threatening to a child, a place where it doesn't want to spend the last weeks of its life.

Yet, until recently, children used to go or stay in the hospital to die. A lack of knowledge and means hampered good quality palliative home care for children and the family doctor had little people to turn to in case of problems. Palliative care for children is not the same as palliative care for adults in smaller doses. A child is not a small adult, and requires some special considerations. The doses of the medications are different and some techniques appear very threatening to children and should never be used in palliative setting, such as intramuscular injections. Emotionally children react differently than adults, according to their age, and the huge entourage (parents, brothers and sisters, grandparents, schoolfriends etc.) only make the problem more complicated.

All this has led people to realise the need for professionals trained in palliative home care for children, and to the foundation of a Children's Committee within the organisation Palliative Home Care Antwerp (PHA). The latter is a network for palliative home care in the district of Antwerp, with intent to optimise the quality of life of the dying patient and his/her family. One basic principle is very important in all this : PHA does not take over tasks of existing organisations for home care, but merely supports and co-ordinates intra- and extramural care. Former experiences in adult palliative patients showed that this kind of approach significantly improved the quality of home care and life of the patients and their families.

The Children's Committee is composed of a general practitioner, two paediatricians, a palliative nurse, a representative from the network PHA, a social worker and people who professionally come in contact with dying children. This committee started a project called "Children and palliative care", offering a structure for the organisation of palliative home care for children and their families, following the same basic principle i.e. not taking over tasks from existing organisations,

merely supporting them. The extent of the care is determined completely by the need of the child and his/her family and is not binding.

Practically, a child is entered by the treating specialist or by the family who informs PHA. In the latter case, PHA will notify the treating physician. A third possibility is the general practitioner contacting PHA, who in turn will notify the specialist. The fact that the family (and the child) are well-informed about the palliative nature of the situation is a prerequisite, as the consent of the parents (and the child) are needed to bring in PHA.

At the start of the palliative care, a first meeting is organised in the hospital with the treating specialist, the general practitioner of the family, a representative of PHA who is responsible for this child, the palliative nurse, a nurse from the hospital where the child was treated, a social worker, a psychologist and home care workers that are involved at that moment. The medical, nursing, psychosocial and spiritual situation and needs of the patient and his/her family are discussed, as well as problems that are expected to arise in the future. The possibilities of home care are mapped and a "work chart" is filled in with the names and respective tasks of all people involved in the home care (fig. 1). The general practitioner becomes the pivot on which the medical treatment hinges, and the specialist stays in the background, but is in easy reach for any possible questions the general practitioner may have.

The co-worker of PHA that is responsible for this child co-ordinates all the care given. He/she is the person to be contacted by all co-workers, and is responsible for advice and support of all first line caregivers. This can range from very practical help such as lending out medical equipment, to giving social support by calling in volunteers. PHA can be reached by telephone 24/24 hours in case of emergency.

The palliative nurse from the hospital is the "bridge" between intramural and extramural care. She is in very close contact with the PHA co-worker. She prepares everything for the discharge from the hospital of the palliative child, and teaches paediatric nursing skills to the caregivers at home if necessary. She informs the specialist in the hospital about the situation at home.

Shortly after the first consultation in the hospital, a second meeting takes place at the home of the sick child, involving all people that will take care of the child and his/her family, including the child and the parents but excluding the treating specialist. The goal

of this meeting is to get the child and the family acquainted to all the caregivers, and explain to them what can (and what cannot) be expected from the help. At the same time, parents and children can express their needs and expectations.

Depending on the need of the family or the caregivers, further meetings will be arranged. It is obvious that very good communication between the caregivers is of utmost importance to report problems, changes in medication etc...

The project started in 1998. Meanwhile, about 20 children were entered, some of them from outside the Antwerp region. In the latter case, the gained knowledge and experiences were successfully shared with the network responsible for that child.

It is very hard to express the value of this project in figures, which is so important in modern medicine. However, every palliative situation is evaluated after-

wards, by parents as well as by all the caregivers. Both parents and caregivers experience the home care given as very positive. Caregivers indicate they have the feeling to be doing something that really makes a difference. Parents can spend their time on things that really matter, such as just being there for their dying child during the time they still have together, because a lot of practical arrangements and worries are taken out of their hands. Furthermore, they know that in case of an emergency, somebody that is familiar with their specific situation can be reached, day or night. This is very comforting and enables parents and children to spend their last moments together in a very calm and intimate atmosphere.

*Dr. E. Michiels., M.D., Ph.D.
Paediatric Oncologist
Koningin Paola Kinderziekenhuis Antwerp
Tel. +32 3 280 21 60 or PHA Tel. +32 3 820 25 31*

Svetlana Shut

Parent activities in Sumy (Ukraine)



I am very grateful for the attention to our charitable fund and our activities. We are engaged in the activities devoted to the children of the Sumy region who suffer from leukemia. The "Viden-Fund" initiated the opening of a pediatric oncohaematological department in Sumy (centre of the Sumy region). At the end of 2000 we started our project "Childrens' pain" under the financial support of the Austrian Kinderkrebshilfe and Caritas-Austria.

We are financially supporting children with leukemia. Unfortunately, the rate of leukemia in childhood in the Sumy region is higher than anywhere else in the Ukraine. Thanks to the project the children get treatment in time, there are no cases of the refusals of treatment due to financial problems in the families of sick children (before the project started it happened very often, since the total income of a family with a sick child is appr. 30-40 Euro but the medicine costs much more than that).

The project gave these children new chances for life and we are very happy and optimistic about it. At the moment we take care of 28 patients.

On the 5th of December, 2002 we organized a very interesting educational conference for the patients and their families. 100 participants attended: 35 children with cancer, their parents, doctors and journalists. We made very interesting reports concerning the problems of cancer in children. We gave the opportunity for parents to express their feelings and talk about their problems. After that all the participants of the conference were invited for lunch where we continued the discussion. We prepared very nice gifts and big food packages for each sick child.

We were very happy when the parents told us that for the first time they felt that they are not alone! It was the highest award for us.

*Svetlana Shut
Director of charitable Viden Fund*



Karin Wandrell

Research for the future

photos by Charlotte Crawell



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 paediatric 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

Regional Group Reports



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 post-doctoral 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.



Barncancerfonden
 Box 5408
 S-11484 Stockholm
www.barncancerfonden.se

Announcements

October 8 - 11, 2003

17th Asia Pacific Cancer Conference

Discovery Kartika Plaza Hotel, Bali, Indonesia (organized by: Indonesia Society of Oncology)

The theme of the conference is "Improving Basic Oncology and Its Clinical Application for Better Cancer Control in the Asia Pacific Region".

The Scientific committee has been arranging in such a way, that various interesting topics on oncology will be presented in order to make a valuable improvement in the Asia Pacific region.

We do hope that by attending the conference everyone involved will gain new information, knowledge and experience as well as exchange views.

Should you need further information in details regarding the event, we will be glad to send you our 2nd Announcement. Send your complete address, telephone and fax number, or contact us at apcc17@cbn.net.id for further information.

Evert DC Poetiray, MD/ President of 17th APCC
Soehartati Gondhowiardjo, MD, PhD/ Secretary General of 17th APCC
Phone: +62-21 392 8829
Fax: +62-21 392 8829 or 62-21 315 4175



October 2-5, 2003

Barretstown Camp, Ireland

ICCCPO Annual Meeting in conjunction with a survivors meeting

Information about registration and program can be obtained from the website soon:

www.icccpo.org or via e-mail to Julian Cutland: cutland@icon.co.za.

October 8 -11, 2003 (Cairo, Egypt)

SIOP 2003

35th Congress of the International Society of Paediatric Oncology

Main theme: Comprehensive supportive care of the child with cancer.

Royal Nile Tower Hotel, Corniche El-Nil, Cairo, Egypt

Please register through www.siop.nl

February 2004

3rd SIOP-Asia Conference

Shabag, Dhaka - 1000, Bangladesh

Fax +88 02 8015576

Email: paed@bangla.net or mamood@agni.com

St. Petersburg

Children for children

This was the motto and mission of the charity performance organized jointly by the Children's Dance Company "Rossiyanochka," the Department of Pediatric Oncology and Haematology of the Saint Petersburg Hospital No.31, and the regional non-government organization "Children and Parents against Cancer".

On December 16th, one of the biggest concert halls of Saint Petersburg, the Music Hall for more than 2000 people, organized a second charity concert with the Children's Dance Company "Rossiyanochka" together with about 60 children (age 6 to 18). Young beautiful actors in spectacular costumes performed dances from many countries around the world to the greatest enjoyment and storms of applause by the audience. These wonderful actors are famous all over the world, have many prestigious awards, received at international festivals. And this day they danced to make cancer patients, their parents, doctors, medical professionals and volunteers happy.

They do not have performances in St. Petersburg very often these days. Thus, it was even more important was that this was already the second charity event for the Department of Pediatric Oncology and the parent initia-

tive "Children and Parents against Cancer". The aim of this event was to raise awareness in the general public and to inform state officials, government and medical professionals about serious medical, psychological and social problems of childhood cancer and to use this event as a preparation for the 2nd International Childhood Cancer Day on February 15th 2003.

The money raised by selling tickets was used to buy books, paint, crayons, albums etc. Right on the stage presents were given to the children, the patients of the haematological ward. The executive director of the regional parent organization presented a beautiful bouquet of flowers to the director of the Children's Dance Company on behalf of 200 members of their organization. The cancer children were very grateful for such a wonderful evening, full of joy and happiness and presented to the young artists pictures they had made while being treated in the hospital.

Among the honourable guests were representatives of the City Government administration, the Commissioner of Children's Rights in Saint Petersburg, Mrs Ogneva L.D., and representatives of the consulates of Denmark and Finland. We would like to express our deepest gratitude to all those people helping seriously ill children.

*Katerina Kisseleva, Executive Director
Children and Parents against Cancer*

Geoff Thaxter and Salma Choudhury

EC visit to ASHIC, Bangladesh

ICCD organiser Geoff Thaxter visited ICCPCO member ASHIC, between 14 and 17 February 2003 to support their International Childhood Cancer Day (ICCD) event. ASHIC is run by Salma Choudhury, founder, whose own child Ashiq died from cancer.

In Bangladesh there is a population of 130m people. The average income is \$320 per year. Some 5,000 children are estimated to get cancer each year, not dissimilar to other countries in ratio. There are only 3 hospitals, all in Dhaka, geared to treating children with cancer – some 26 beds in all.

Perhaps only 5% get treatment. Many of these children are admitted at the hospital at an advanced stage of the disease, when the cancer is incurable. For the others their parents face the problems of paying for treatment, assuming drugs can be made available.

Despite the problems, people are dedicated to helping these children. Doctors, try to do their best in difficult circumstances. ASHIC also helps to deal with the social, emotional and practical issues of cancer.

ASHIC is running a few projects like Play Centre at hospitals, monthly outing programs and patients' services for children who are undergoing treatment such as counselling of parents, support for medicine financial, transportation, blood collection, contact doctors, food etc. One of the project started by ASHIC was to create a "Shelter". This is an accommodation facility for cancer children and their families

Imagine having to take your child 200 miles to a hospital, to be told that the child has cancer. And that the treatment will take 12 months and cost 3 year's family income. This is the situation that faces many of these families. Many turn around, go home, and never return. The child is almost certain to face a painful death.

ASHIC's Shelter helps to address this problem by providing families with a place where they can stay, free of charge, while their child is treated. The home is basic, but can house 10 families, and provides sleeping accommodation, cooking and washing facilities, a living area and equipment to keep families occupied. ASHIC also arrange for regular visits by doctors and a weekly counselling session.



Niskriti with her father at the ASHIC Shelter. Her treatment is going well.

The doctors now report that many more families complete the treatment because they have somewhere close to the hospitals to stay. This improves the chance of survival.

The shelter is for also important in helping families to bond and support each other. The families all face similar emotional and practical circumstances and so are able to give support to each other.

Despite the good that ASHIC does, it needs help. The shelter costs around \$850 a month to run. This is very little in developed countries but a lot in Bangladesh. Funding is found from month to month, often from the pockets of the founders.

While Geoff was in Dhaka, he met with all ten families currently staying at the shelter. For one family with an only child, they were told on the International Childhood Cancer Day, that treatment would no longer help their child. The following day this family left to go back home, uncertain of the future, except that their child would soon die.

There is no palliative care – pain relief and emotional support available in developed countries to help patients to have quality of life in the time they have left. For this family, and tens of thousands others each year, there is only the prospect of a painful death. This adds to the burden parents will always carry with them.

It is too late for this family. If the ICCD can raise awareness and get action, it will not be too late for others that follow. If you would like to know more about ASHIC, or help, please contact Salma Choudhury at e-mail: ashic@citecho.net

Sue Grant

Standing on his own two feet

Foreword by David Clark, Professor of Medical Sociology, University of Sheffield, UK and Sister Frances Dominica, Founder of the Children's Hospice Movement.

Written from the perspective of the mother – a British journalist living in Germany – this beautifully crafted, honest, extremely readable and occasionally humorous biography traces the life of her son Alexander, building up to his diagnosis of bone cancer (osteosarcoma) at age 20, the physical and psychological effects of his treatment, his preparation for death and how the family learns to survive without him.

By the time the author describes the aggressive chemotherapy, surgery, her son's consequent disability and the serious disruption to everyday life, the reader already feels part of this bi-cultural family. The issues addressed, from initial denial, to communication with each other and with nursing staff, intensive pain control management and dealing with the life-stage problems of terminally ill-young adults and adolescent siblings, transcend the individual story. Unique, however, are the astute observations of the different healthcare systems in Britain and Germany.

When treatment fails, the book demonstrates the struggle to persuade the medical establishment that with the right sort of palliative care Alex's wish to die at home could be achieved. Those responsible for the care of the dying – of any age – would benefit from reading about how much it mattered to Alex and his parents that he should be able to remain in familiar surroundings.



Braiswick, England, 2003,
ISBN 1-898030-78-2
This book is available in English and German.
More information at www.suegrant.de

Central to the whole story is the personality of Alex, his drive to be independent against all the odds, not idealised by his family but loved completely. The reader watches him mature, accompanies him in his despair and rejoices when he and his family finally find peace of mind.

This book will appeal not only to families who have lost a child/young adult to cancer, but is also highly recommended reading for healthcare professionals, palliative care workers, international cancer organisations, teachers and psychiatrists.

The English version may be ordered from the publisher's website at www.author.co.uk/grant
Or through www.amazon.co.uk or from www.suegrant.de

The German version (with a foreword by Dr. Marianne Koch) ISBN 3-00-010415-1 is available at www.suegrant.de

Announcement

August 15-19, 2003, Montana (USA)

Young Adult Survivors Conference (YASC)

A 4-day retreat designed to address issues of survivorship, to provide information and tools for self-advocacy and to build bridges of support between young adult cancer survivors who may be experiencing similar journeys through life (for 28-25 year old patients and survivors).

For more information please contact:

Camp Māk-a Dream at +1 (406)549-5987

or e-mail: camp@montana.com or visit their

website: www.campdream.org

Books

Executive Committee

Marianne Naafs-Wilstra, Chair

Schouwstede 2d
3431 JB Nieuwegein, The Netherlands
Tel. +31 302422944 fax +31 302422945
e-mail: mcnaafs.vokk@wxs.nl

Simon Lala, Vice-chairman

15 Jack Conway Lane (Box 76442)
Manukau City, New Zealand
tel. +64(9) 575-7785, fax +64 (9) 262-2132
e-mail: simon.lala@xtra.co.nz

Christine Wandzura, Secretary

609 14th Street, NW, Suite 205
Calgary, Alberta T2N 2A1, Canada
tel. +1 (403) 216-9210, fax +1 (403) 216-9215
e-mail: wandzura@kidsoncercare.ab.ca

Mark Chesler

University of Michigan, 4028 LSA Building
500 South State Street
Ann Arbor, Mi 48109, U.S.A.
tel. +1 (734) 64-3654, fax +1 (734) 647-0636
e-mail: mchesler@umich.edu

Julian Cutland

50 Dawn Drive, Northcliff
2195 Johannesburg, South Africa
tel.+ 27 (11) 678-3803, fax +27 (11) 678-4863
e-mail: cutland@icon.co.za

David Orren

8 Hamlacha Street
47445 Ramat-Hasharon, Israel
tel. +972 (3) 618870, fax +972 (3) 6138871
e-mail: DavidHad@inter.net.il

Geoff Thaxter

1 Betjeman Close, coulsdon
Surrey, CR5 2LU, England
tel: + 44 1737 555411
e-mail: thaxter@ltrust.freemove.co.uk

Edith Grynszpanchoc

Mansilla 3125
1425 Buenos Aires, Argentina
Tel- Fax 5411 4825 5333
e-mail: comoayudar@fundacionflexer.org

Ira Soelistyo

c/o Rumah Sakit Kanker Dharmais,
Jln. Letjen. S.Parman kav. 84-86, Slipi,
Jakarta 11420, Indonesia
Tel. 62-21-5681612 or 62-21-5681570 ext. 2030
Fax. 62-21-5681612/7547745
e-mail: yoai2008@indosat.net.id

Secretariat:

c/o VOKK, Schouwstede 2 d
3431 JB Nieuwegein, The Netherlands
tel: + 31 (30) 2422944, fax +31 (30) 2422945
e-mail: icccpo@vokk.nl

Members of other ICCCPO committees:

Gerlind Bode (newsletter)

Joachimstraße 20
53113 Bonn, Germany
tel: + 49 (228) 9139430, fax +49 (228) 9139433
e-mail: DLFHBonn@t-online.de

Pia Bonini Serrafiero (newsletter)

8° Strada 9b, San Felice
1 Segrate MI 20090, Italy
tel:+ 390 (2) 7533387, fax 390 (2) 7533387
e-mail: pia.bonini@tiscalinet.it

Sadie Cutland (PODC)

50 Dawn Drive, Northcliff
2195 Johannesburg, Couth Africa
tel.+ 27 (11) 678-3803, fax +27 (11) 678-4863
e-mail: cutland@icon.co.za

Mokhtar el Harras

Association l'Avenir
Route de Qued Akrach-Hay 11
Angle Rue Bani Jadr et Bani
Rabat, Morocco
tel/fax: +212 (37) 71 33 57
e-mail: mokhtar@iam.net.ma

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