

ICCCPO Newsletter

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Si preferien recibir este boletín en la edición en castellano, por favore porganse en contacto con la Secretaría de ICCCPPO en Hollanda.

First International Childhood Cancer Day:

4 out of 5 children denied cancer treatment

This shock statistic was revealed by ICCCPPO at the launch of the first International Childhood Cancer Day in January.

An estimated 250,000 children develop cancer each year worldwide, but 80% do not have access to treatment available. Most children's cancers are curable and if the necessary resources and expertise were available across the world, more than 100,000 lives could be saved each year.

In developed countries, where survival rates are particularly high, more than 70 per cent of children with cancer are still alive 5 years after diagnosis. But because so many countries lack adequate cancer care facilities, the world's overall survival rate is as low as 20 per cent.

ICCCPO was founded to try to improve this situation. It aims to aid the flow of information about childhood cancer, campaign for better access to treatment and support the needs of young cancer patients and their families.

Marianne Naafs-Wilstra, chair of ICCCPPO said, "Every child with cancer deserves a chance to live. Together we can give them that chance".

www.icccpo.org

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Here is what some professionals around the world had to say about the International Childhood Cancer Day:

Prof Vaskar Saha of the Cancer Research Center UK: "The International Day is an important opportunity to highlight the inequalities in treatment across the globe".

Prof Giuseppe Masera from Italy: "The members of the larger childhood cancer family need to work together to increase the partnership initiatives between centres from developed and low income countries"

Prof HansPeter Wagner of the International Society of Paediatric Oncology supported the event by pointing out the need for "early diagnosis and referral for treatment".

Andreas Ullrich of the World Health Organisation explained "parent organisations play an important role in advocacy and care programs".

Ian Magrath of the International Network for Cancer Treatment & Research: "The International Day will encourage all those who work in support of children with cancer".

Events took place in 30 countries to celebrate this first International Day. Information is being collected about the events in each country, but here are some highlights:

UK: In the UK, events took place at St James in Leeds with celebrations in the Children's Unit, at Alder Hey in Liverpool with Everton players visiting, and at Adenbrooke's with a presentation to doctors and nurses by the parent organisation. The London launch by CRUK and ICCCPPO was covered in four national newspapers, SKY and local Radio.

Bangladesh: A human chain of children, doctors, parents and volunteers in Dhaka paraded in the city to raise awareness of the day. Gifts were distributed to children with cancer at two hospitals and a shelter. In Chittagong there was a further colourful rally involving school children and volunteers.

Iceland: A huge pop concert was held in Reykjavik on 13th with eight groups and musicians with all proceeds going to the parent organisation – SKB. The parent organisation also gave computers on 15th to the hospital school room. Both events provided good coverage on national TV, press and radio.

Netherlands: The Dutch Parent Organisation released, on 15th, the Arabic translation of "Chemo-Kasper", a book to help children and families understand cancer treatment.

Romania: The National Comedy Club put on a charity concert in aid of the parent organisation.

Russia: In St Petersburg, a party, special food and gifts was arranged for the children in hospital on 15th and for outpatients and families on 20th.

India: In Chandigarh there were painting competitions for the children in hospital, a seminar attended for families and professionals, and a rally of schoolchildren.

Greece: The government announced financial support for the parent organisation to coincide with 15th, in support of a new hospice the PO had built. A seminar to raise awareness of childhood cancer was also organised.

Other countries taking part were:

Argentina Israel Australia Italy Austria
Luxembourg Mexico Canada Morocco Colombia
Croatia New Zealand Finland Portugal Germany
South Africa Spain Indonesia Switzerland Iran
Ireland Yugoslavia

For more information contact Geoff Thaxter at thaxter@ltrust.freemove.co.uk

Excerpts from a presentation at the SIOP/ICCCPO conference in Brisbane (Oct. 2001)



Some facts about Finland:

- Population is 5.2 million
- Forests cover three quarters of the country's surface area of 338 000 sq. km. Other outstanding features of Finland's scenery are some 190 000 lakes and approximately as many islands.
- The highest daytime temperature in southern Finland during the summer occasionally rises to almost 30°C.
- During the winter months, temperatures of minus 20°C are not uncommon.

Organising school education for children with cancer in Finland

Leena Vasankari-Väyrynen

Children with cancer are treated in university hospitals. Annually 140 new cases of children with cancer are diagnosed. We have a high class health care, where every patient gets treatment.

The Finish parent organization for children with cancer is called SYLVA. It is a national organisation of about 1500 families in various parts of Finland. It was established by parents of children with cancer with the aim to help patients and their families. We believe that it is important for children with cancer to continue school during treatment because:

- Seriously ill children see school in an entirely new light
- It helps children to maintain a "normal" life
- It gives them faith in the future

However, there are various problems in arranging school for children with cancer. Thus, the teachers and rehabilitation counsellors from 5 Finish children's cancer units listed the problems observed in the education of children with cancer. Information was collected from patients, hospital

Help for Children with Cancer from Italy

Parents of children with cancer and professionals from all over Italy met in Milano in a national conference to celebrate the 1st ICCD. The Italian Federation (FIAGOP) who promoted the Conference decided to dedicate the day to raise awareness on the situation of children with cancer in low income countries who are denied not only the possibility to be treated but also the hope to be cured. A

number of parents associations and pediatric cancer units presented their ongoing programs of international cooperation with poor countries comparing experiences and results. The outcome of the Conference was the launch of the program "5% for Hope" through which Italian parents associations of children with cancer will contribute to international cooperation programs giving 5% of their annual income.

“Hospital at home” for children with cancer A proposal for palliative care.

Luisa M.E. Massimo

Introduction

Health care of children and adolescents with cancer continues to grow in complexity. While in many cases physicians are winning the fight, quality of life (QoL) is always a problem to face and a challenge, mostly when it is the principal important goal. Today, the strategic approach of pediatrics is the adoption of a global therapy, which includes among active interventions home care, particularly useful to terminally ill patients affected by any disease.

The costs of hospital care are high everywhere, especially those for salaries of staff doing shift work during the whole week. Detailed analysis comparing costs of hospital care towards home care delivered by the same hospital showed that the latter are reduced and that home care is better accepted by patients and families. Because of increasing pressures from shrinking health care budgets, several governments encourage a widespread use of home care to old people, to patients with cancer, mental diseases or AIDS, to early discharged patients, and generally to those affected by any disease treatable at home with constant specialized help and guide by the hospital.

Home care in pediatrics

During the long diagnostic and therapeutic course of a child with a chronic disease pediatricians should always consider whether hospital care is mandatory. When home care delivered by the hospital is adequate, it should be chosen not only to reduce costs but mostly for psycho-social reasons. Families and especially mothers have always been directly involved in the treatment and care of their child, mostly when affected by a severe disease. Today, this involvement is strongly

suggested and almost imposed by physicians. Since diagnosis, parents and often other family members are given detailed instructions and information. For this reason, it is not difficult for the family to accept home care as an alternative to hospital care. Many large and important studies on home care are reported in the literature. This process in health care is worldwide, involving both rich and poor countries. Race and culture do not seem to play any role.

Strong motivations support pediatric home care. The life rhythms are better preserved if the whole family is at home. Parents must be taught how to cope and how to talk with their children, the sick ones and their siblings. The dialogue is easier at home. Home care respects the needs of the siblings. Adjustment to daily life is easier at home, taking into consideration the active help of relatives and close friends. Children need stability and honesty.

Pain is a source of great distress for children. When possible, pain control must be obtained or at least tried at home. The child may find a better comfort when in his own bedroom and, if he feels better, he can play at home. When the child is dying the treatment is focused on a good QoL and no more on cure: school aged children and adolescents can feel the change. The difference is impressive if they are followed at home and not only in hospital. Volunteer Associations can help the child's family better at home than in hospital.

Home care for terminally ill children and adolescents

Home care can be very useful in the terminal stage, when QoL is the primary goal. The WHO has defined palliative care as "integrating the psycho-

logic and spiritual aspects of patient care, affirming life, and regarding dying as a normal process; neither hastening nor postponing death, offering a support system to help patients live as actively as possible until death; and offering a support system to help the family cope during the patient's illness and their own bereavement." Recently this aim is considered also for children. Pellegrino underlines the emerging ethical aspects, the responsibility of physicians towards a terminally ill patient in pain, the inadequacy of palliative care when delivered by not adequately trained physicians. Pellegrino also considers the ethical aspects of euthanasia, defined as 'assisted suicide' and the so-called 'slow euthanasia', consisting in high dose sedation of pain not aimed at causing patient's death. The reasons for home care of terminally ill children are many and have been illustrated not only by pediatricians and nurses but also by other health care professionals, such as ethicists, psychologists, sociologists, educators.

The home care team

Home care cannot be delivered by volunteers with humanitarian vocation. It must be skilfully planned. The team is generally coordinated by a physician in charge and includes physicians, many specialized nurses (who represent the mainstay of this activity), social workers, psychologists and a family/home caregiver. In most countries health professionals now rely on family caregivers or home caregivers. A large variety of literature reports on home care, which is looked at in different ways according to the different local situations. The creation of a bridge between hospital and home is always suggested. Hospital nurses at home provide adequate psychological support and information, minimizing the risk of complications, delivering nursing care, administering antibiotics, chemotherapy, analgesics, parenteral nutrition, etc. The family caregiver is a family member ready and capable to learn and carry out this task. It is not always easy to find such a person inside the family. Thus, it is necessary to engage a 'home-caregiver', a trained professional, usually a nurse, keeping in touch with the family of the patient to whom the home care is delivered by the hospital. Home care lasts at least two months.

The caregiver and the home care staff should be able to give the patient and his/her family confidence, support, immediate help in case of emergency, help in case of non emergency but important problems, high cultural level, attention and pain control, help during the dying process, help after death. The American College of Physicians has recently published the caregiver guidelines, which can be consulted on the web. The Penn State



Milton S. Hershey Medical Center has created a web site on home care for children with cancer, which is constantly updated. Both organizations indicate four key ideas for the education and training of a caregiver, in order to succeed in solving problems. These key ideas can be remembered by thinking of the word COPE:

- C for Creativity,
- O for Optimism,
- P for Planning,
- E for Expert information.

The education and training of a home caregiver is very complex. He/she is in charge of the organization of the COPE items. According to the above-mentioned guidelines, 'planning' includes the knowledge of each patient's and his family's problems, of the moment when to ask for the help of the physician, coordinating nurse, social worker, psychologist, etc., a large range of duties, the ability of carrying out and, when necessary, modifying the planned intervention, the development of an orderly and systematic plan, the choice of the best strategy, the evaluation of obstacles. The guidelines can be improved, mainly thanks to the support of experts. All the authors reporting on their experience in home care of children and adolescents underline the importance for home caregivers to know very well the most frequent symptoms, to learn how to control pain, and to know both pain origin and analgesia.

Conclusions

Today, several measures are necessary. First, home care should become part of health care programs of most countries. Each one should provide guidelines for a correct approach to the problem, and to allocate adequate funds. Children's Hospitals and Research Institutes can start home care following the indications provided by the international literature. It is to be hoped for that a larger number of professionals with different competences will take charge of home care and that the strategy used will gain not only moral, psychological, social rewarding, but also financial recognitions. Concerning pediatrics, this project should be implemented as soon as possible, since hospitals, especially those carrying out teaching and research activities, are rarely on a pediatric scale,

they can be upsetting for the child, and psychological troubles and traumas can be a consequence. Home care delivered by the children's hospital can become an alternative approach for those patients, especially terminally ill, who do not require hospitalisation. In conclusions, it should be necessary that scientific pediatric societies, health care professionals and Parents' Associations push politicians and implement the integration of several types of services for treatment of children, including home care, offering their collaboration in the global therapy design.

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A detailed list of references can be obtained from the authors.

A Parents' Initiative in Crimea, Ukraine

Eugene Novitsky,

We are a voluntary community. However there is hardly anyone who would join us voluntarily. 'Us' means those parents, whose children suffer from different forms of leucosis and other oncological diseases. This unites us. 20-25 children in Crimea are annually stricken with acute leukemia, 10 with lymphogranulomatosis, 10-12 with lymphoma (lymphosarcoma).

Before IT happened in our family, we considered leucosis (the same as leukemia or blood cancer) to be an incurable disease that kills quickly and tortuously. From our school days, we remember the story of a Japanese girl who did not complete the thousand paper cranes she was making for the doctor who had promised her she would recover. Today, however, leucosis is treatable. Not always, though, and with varied success. Yet we have realistic hope.

In 1991, the parents of 10 year old Alex Ametov issued a national call and thereby gathered enough money to take the boy to Germany. Another girl, who should have gone with him died two days before the day of departure. That half official trip started a new stage in the lives of three hematologists from the Crimean Republican Children's Hospital – the Chief of the Department, Valentin Usachenko, and Olga Ivanova. The father of the dead girl gave all collected money to the hospital and said to Usachenko: "It would be better you go, and then you will cure our children here."

What happened afterwards you may know from this newspaper article:

„Crimean pediatric hematologists are some of the first to master the methods of German specialists on the treatment of leucosis and to be successful in their work. Using modern methods of treatment, they have a high survival rate among those children who had been considered terminal – 70%. Before 1991, it had been only 3%.

The leading German hematologists Schellong and Reiter started to support the Crimean doctors and helped them with medicines. The results of the first three years were up to the ones in German hospitals That is why the Crimea has one of the best hematological departments in Ukraine.

Since April 1993, Professor Schellong has been leading the work of a leukemia group that includes 9 Ukrainian Departments. Doctors from Simferopol sit on the Board of Directors. Today, under the guidance of Doctor Reiter, the staff of the Hematological Department of the Crimean Republican Children's Hospital is developing a new program for Ukraine, thus becoming the main center of research for a form of malignant non-Hodgkin's lymphoma and its treatment".

Now about us, the parents: The „Parents' Initiative" was the „connecting link" that allowed Simferopol to discover the German methods and specialists. We organize holidays for the patients and are looking for finances, medicines (finding them is not such a problem, you have to manage to get them!)

The moment our kids become patients our families enter into a new life. Lots of things we had never thought of or known before become the

reality of everyday life. We (mostly mothers) go to the hospital along with our children and stay there during the whole course of treatment which is about 7-9 months. Now we talk and even joke about things that before would have been thought of as nightmares. We do not have to LEARN how to be together – no time for that, we have to BE together, supporting, encouraging and clinging to each other. What we never thought before or did not want to think, or had doubted is becoming so glaringly obvious and clear now that there is no need for words to either express or prove anything.

Our children are aware of their diagnosis and it's severity – and that is right. No matter how old a person is he has to fight his disease consciously, knowing how dangerous the enemy is. When we get into the hospital (the first week is especially hard for us, parents) we are given a book „What is leukemia?“ This book has been translated from German and contains cheerful pictures, drawings by kids, who went through the whole severe course of treatment. So we and our „brains“ are reading this page-turner (paradox?!..) and a detailed story of the origin of the disease and the ways it will be treated ...

By the end of the first week we realize the break down of our preconceived notions of leukemia. We are not in a death department. They come here to fight for life, armed by an unflinching determination and a hope to win. Realizing what is wrong



with them, our kids are more tolerant of the pain and other unpleasant ways the body reacts to the complex treatment. They get used to the IV and do not cry when they are hooked to it for a day or two or even a week. Thus, this little book and those who surround us – doctors, nurses, caretakers – give us a precious gift of hope.

Not all of our children survive the treatment. We do remember that; and remember those we will never see again. Yet against all the odds we hope and believe – and will believe tomorrow again.

Eugne Novitdky
coordinator of the Crimean „Parents' Initiative“

The Day of the Cured Children

Anniversary: 10 years since the BFM-protocol was established in Crimea

It is an annual tradition in the hematological clinic to celebrate “the day of the cured children” on June 1st. It is so nice when it is a USUAL thing for children who have suffered leukemia – blood cancer – to get healthy!

But this year it was a special holiday, an anniversary. 10 years ago the staff of the hematological clinic under the chief-doctor Valentin Usachenko has first started using the German medical anti-leukemia program BFM (Berlin-Frankfurt-Munich). So instead of a huge rate of deaths we had an incredible number of saved lives: 75%.

Those whose lives were saved at the clinic, have come here for the holiday. There were lots of them, the hall was overcrowded. Tons of flowers. Applause when the doctors walked into the hall. They have helped each of these children to stay alive.

A lot of children have already grown up. More and more of them come to this annual holiday with their own children. Now there are not only their parents beside them, but their mates. A new adult life has started. But they cannot forget what they've undergone here, in the clinic, during long months of suffering.

The nurses helped the children who are treated in the department now to get down to the hall. They wear gauze bandages, they're still weak and don't have hair. But they have shining eyes looking at those who have already won over the disease: „We will also be able to make it through!“ This year Lena Lifanova, who was the first patient to be treated from leukemia on the basis of this German program in 1991, came to the holiday.

The holiday started with games for children organized by the psychologist. Then there was a concert given by dance-groups. And then the real

excitement for the audience came: the clown Tolyan (Anatoly) is everybody's favorite – children's and adults', patients' and doctors' and of the guests of the clinic. This time the circus artist Anatoly Lyadnov brought with him a whole team of young gymnasts and jugglers from the circus. They presented their short program 'Circus, circus, circus!'

Then they went to the ward to entertain those children who were not able to get down to the hall to join the holiday. This time Tolyan even went to the reanimation department to visit a girl who was undergoing blood-cleaning. He entertained everybody who was with her by walking on his hands.

And can there be a holiday without presents?. Finally it was their turn: candies and oranges to raise the mood, books to wander with their characters, and funny „speaking“ clocks.

There were 16 children and teens who have received the „Diplomas of former patients“. They were those who went through the treatment 5 and 10 years ago. Among them was Masha Vasilenko who came to this holiday with her one year old child.

Many guests came to celebrate this holiday with us: hematologists from Kiev and Lviv. There also came professor Guenter Schellong from the German city of Muenster. He is one of the leading European hematologists. Thanks to his efforts we are able to accomplish complex and expensive anti-leukemia treatment in Ukraine. Still, the

German professor wasn't let just to sit still and enjoy the concert. The clown Tolyan took him out to the stage and put on him a funny wig and nose. The holiday was filled with joy and laughter. This is the day of our victory.

The preparations for the celebration were done by the hematologists along with the members of the „Parents' Initiative“.

The celebrations came to the end, but life goes on. What will it bring these children? In many ways it depends on us adults, depends on our readiness to help other people in their trouble, depends on how each of us is able to love others, which means to cut off one's own pleasure to help somebody else out. That's what is really difficult! But can we live without that?

People were leaving the clinic with presents in their hands and smiles on their faces. They carried with them their 'diplomas' that they received from Valentin Usachenko's hands. They won't forget the words written there:

**Defeating hell and pain for the sake of future life,
You are the winner in the deadly struggle.
Let be your life as bright as the summer sun,
The road you chose, be even brighter,
Destiny may save you, dear child!
Live a long and happy life but don't forget.**

Marina Strogaya
Andre Trofimov
Crimea, Ukraine

Announcements

April 14 – 17, 2002

5th Continental Meeting of SIOP in Africa
in Yamoussoukro, Côte d'Ivoire (Ivory Coast)
Cure of Children with Cancer in Africa:
The Challenge of the Third Millennium
For more information contact:
Mokhtar el Harras
E-mail: mokhtar@acdim.net.ma

June 28 - 29, 2002

7th International Conference on Long-Term complications of Treatment of children & Adolescents for Cancer
Niagara-on-the-Lake, Ontario, Canada
For more information contact:
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(Conference Coordinator)
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Roswell Park Cancer Institute
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Tel. (716) 845-2334



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16 –18 Sept., 2002

ICCCPO-SIOP meeting 2002

In Porto (Portugal)

The dates for this year's ICC-
CPO conference have been
tentatively set to
begin Monday evening
September 16 to
Wednesday September
18. The SIOP meetings
will also begin on
September 18th and
continue on through
to Saturday
September 21, 2002.

In preparation for
this meeting which is to take place in
Porto, Portugal, you find information regarding
the registration and abstract form which on-line
at the following address:

www.congrex.nl/siop2002/update1.html All pre-
senterers within the ICCCPPO portion of this meet-
ing are encouraged to submit a formal abstract in
order that it be considered within the parent's
section of this meeting.

This Congress Update provides you with congress
information of general interest and information
from the SIOP 2002 Congress Secretariat and
Local Organising Committee.

This first issue contains the Call for Papers. It
provides you with the electronic abstract form
and guidelines and instructions to assist you in
submitting your abstract.

In addition, this first Congress Update contains

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Nominations to the Executive Committee of the ICCCPO

The Annual General Assembly („AGA“) of the ICCCPO will take place the morning of Wednesday, September 18, 2002. At this time we will be electing or renewing the terms of three directors to the Executive Committee. On behalf of the AGA, please consider a candidate for this role.

Being a member of the Executive Committee is an important contribution that any member can make to this vibrant organization. Nominees do not have to be parents of children with cancer, but they must belong to a group who is a full member. There is a commitment of both time and money. Successful candidates must fund their own way (either personally or through their association's resources) to two meetings per year. All EC members sit on at least two working committees and carryout many duties throughout the year. Most of our members put in an average of 10 to 15 hours a month on ICCCPO work.

When creating the slate of candidates, the current EC considers regional representation (to ensure all parts of the world are represented), working skills (marketing, policy making, fundraising, management, programs, etc.) and a willingness to go above and beyond in helping parents of children with cancer throughout the world.

Kindly place this item on the agenda of your next board or committee meeting in order to give some serious consideration to nominating a member from your organization who is ready to take the next step in helping children with cancer. Nominations close June 18, 2002.

You can make your nomination in confidence by contacting the Chair of the 2002 Nominating Committee, Christine Wandzura by email at: wandzura@kidscancercare.ab.ca or by fax at +1 403 216 9215. If you would like to know more about the time and monetary contribution or any other enquiries, please contact Christine.

SIOP – what is SIOP?

(International Society of Paediatric Oncology)

Excerpt from the newly elect president of SIOP, Prof. Alan Craft, about his personal visions:

SIOP has developed and changed over its 34 years of existence and the growth of our continental branches has been an important innovation in recent years. The time is right for us to take a serious review of our activities and to determine what is the best role of SIOP International and its continental branches. Each continent hat its own unique needs and the role of SIOP needs to be supportive of these. My own view is that we have two major missions: One is to run the best paediatric oncology meeting in the world, and I think that we now achieve this. The other is to try and bring the most appropriate cost-effective care to children with cancer wherever may be. Our PODC activities (Paediatric Oncology in Developing Countries) are vital to our future. (...)

SIOP News, Dec. 2001, No 24, Report from the president



Sibshops

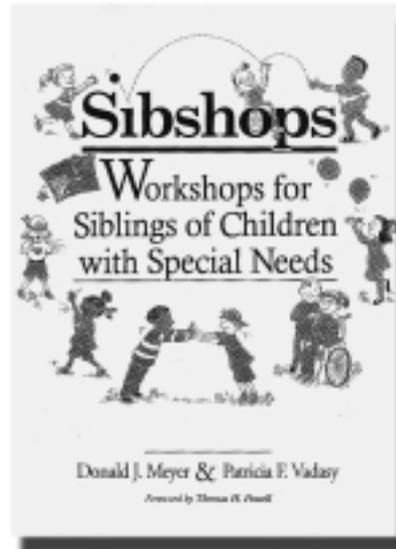
Workshops for Siblings of Children with Special Needs

Donald J. Meyer & Patricia F. Vadasy
Paul H. Brookes Publishing Co, Baltimore
ISBN 1-55766-169-3
www.brookespublishing.com

Siblings who do have brothers and sisters with special needs or health concerns, like cancer, have needs of their own – needs that are often overlooked. Growing up with a disability or life-threatening disease in the family is often stressful and unfair. But it can also be a source of inspiration. This practical resource details Sibshops, the award-winning programme that brings together 8- to 13-year-olds to express their good, and maybe not so good, feelings about having siblings with disabilities. Sibshops seek to provide siblings with opportunities for peer support. The programme is designed for school-age children and is therefore provided within a lively recreational atmosphere so that children have fun while they learn. Sibshops are not therapy, group or otherwise, although their effect may be therapeutic for some children. They acknowledge that most siblings are doing well, despite the challenges of an illness or disability.

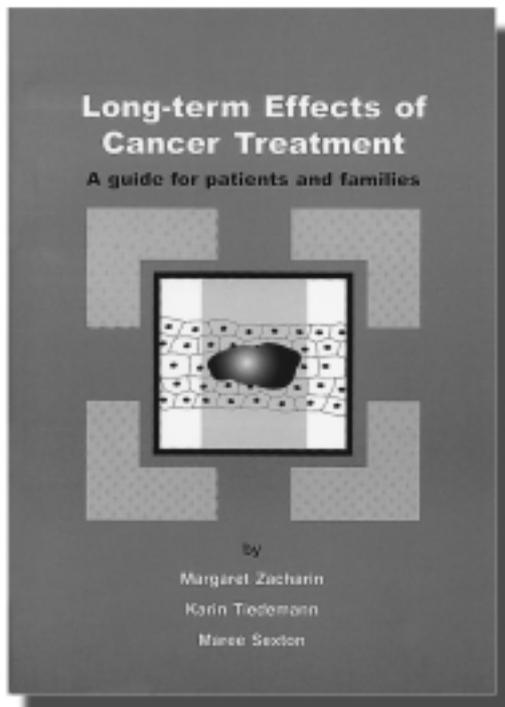
From start to finish this illustrated book describes how to organise a Sibshop... It is a practical guide for teachers, psychologists, parents and other professionals to provide much needed support that encourages learning, sharing, and having fun. The book is not cheap, but highly recommendable.

Marianne Naafs-Wilstra



Infos ... news ... miscellaneous ...

The Lisa Thaxter Trust in the UK just funded a website for siblings under: www.siblinks.org



Long-term Effects of Cancer Treatment:

A guide for patients and families
by Drs. Margaret Zacharin,
Karin Tiedemann and Maree Sexton

is available at Miranova Publishers
PO Box 1041
Camberwell
Victoria 3124
Australia

Book details and prices can be obtained from the
www.welcome.to/miranova

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