Notes from the editors

There have been interesting developments for ICCPO recently. The board met for three days in the family house of our associate member Click Sargent in Prestwick, Scotland. One of these days was spent entirely on strategic planning, which resulted in an action plan for the next five years that forces the board members and the committee members to work even harder. We know, however, that among our membership there are many dedicated and experienced people who may wish to help us to do our work, e.g. by the planning of regional meetings, working in ICCPO committees etc. If you wish to make a contribution, please contact one of the board members. Their addresses are on the last page of this newsletter.

The ICCPO regional meeting in Bali, Indonesia, was very successful. A short report in this newsletter will give you some impressions. A more detailed report is available from the Secretariat.

In May 2007, a meeting for former Yugoslavian countries will be organized in Sarajevo (Bosnia-Hercegovina), and in August 2007, a meeting for Russian speaking groups in St. Petersburg (Russia) is on the agenda. Details are to be found in this newsletter.

We have no final programme yet for the ICCPO-Meeting in Mumbai. But we will publish it on our website as soon as it is available. Please keep in mind that the deadline for applying for a stipend was May 14!

What else is in this newsletter? You can read more about the recently founded World Child Cancer Foundation (WCCF), we publish some of the lectures from Geneva, and we give information about two projects in which ICCPO is involved. In October 2006, ICCPO representatives took part in an interesting multidisciplinary working conference in Erice, Sicily (Italy) about “Cure and Care after Childhood Cancer”. The so called Erice Statement was the result of two days hard work. Feel free to translate this statement and use this in your advocacy activities, if possible jointly with doctors, nurses, psychologists and epidemiologists.

We wish you much success with your organisations and keep us informed about your activities!

Marianne Naafs-Wilstra
Gerlind Bode
The Unmet Needs of Children with Cancers

Childhood Cancers: Rare diseases, but the major cause of death by disease in children over 1 year old

In Europe 12,000 children annually are affected by cancer. Despite high cure rates (ca. 70%), cancer is still a life-threatening disease in children and remains the major cause of death from disease beyond the age of one year: 3000 children die each year from cancer in Europe.

In addition, cure is often only achieved at a substantial "cost" (major organ toxicity, developmental abnormalities and second tumours). These long-term sequelae constitute a significant healthcare burden and can reduce both life expectancy and quality of life for childhood cancer survivors.

There is, therefore, an unequivocal and urgent need for more effective and less toxic treatments to improve both qualitative and quantitative outcomes for children with cancer.

Poor access to innovative therapies for children with cancer in Europe

In the last two decades, a new generation of drugs that target molecules with a role in oncogenesis has become available. The development of these novel targeted drugs is based on a rational approach, from a starting point of extensive knowledge of the biology of human cancers, followed by a stepwise development of compounds targeting specific molecules in cancer cells. A large number of new compounds are in pre-clinical evaluation and early clinical development in adults. Some of them have already been registered for market use. Access for children to innovative therapies developed by pharmaceutical companies has so far been extremely limited in Europe, one reason being that paediatric oncology does not represent a large, and hence financially attractive, area for drug marketing.

Major European initiatives to enhance drug development in children

The European Commission has recently issued a New Regulation called "Medicines for Children". This Regulation stipulates evaluation in children before a new drug can obtain a marketing registration from EMEA. Moreover, marketing rights will be extended (presumably for at least 6 months) when an appropriate research file is available showing that clinical studies have been performed in children. Recent similar regulatory initiatives in the US have significantly increased drug research and development in the paediatric population of any type of drugs, including anticancer compounds. The challenge is now to select and prioritise among all new anticancer compounds entering a clinical development in adults those needing a paediatric development, and then to provide the resources to conduct their clinical evaluation in a timely fashion, with respect to the ethical and medical needs of children suffering from cancer.

Goals of ITCC (Innovative Therapies for Children with Cancer)

ITCC aims to provide a combined biological and clinical drug evaluation programme to select and apply the most promising novel compounds for their use in childhood cancer, with the following objectives:

- To select and prioritise anticancer compounds being developed by pharmaceutical companies for use in adults, that are likely to be active in paediatric cancers, through a comprehensive pre-clinical R&D drug evaluation programme. ITCC has designed a rational mechanism-based strategy for compound prioritisation based on target gene and protein expression profile, target validation and pre-clinical evaluation in relevant in vitro and in vivo models.

Biology and Preclinical Evaluation Programme:
Demonstration of proof of concept through Phase I/II trials of novel agents, by establishing:
- a clinical trials network with critical mass (numbers of investigator sites and patients),
- access to contemporary technologies (biology, imaging)
- use of new methodology and designs.

Clinical and Translational Programme:
Improving information access and ethical aspects of clinical research in children with life-threatening diseases.

Parents, patients and their representatives are involved throughout the project, and the International Confederation of Childhood Cancer Patient Organisations (ICCCPO) is a full-partner of the ITCC Consortium.

ICCCPO initiative

In the Fall of 2006, representatives from parent organizations from the five participating countries (France, Germany, Italy, United Kingdom and Netherlands) met in Amsterdam to discuss how to proceed. A parent committee will be formed within ITCC to work towards the goals that were agreed on at the meeting, e.g. reviewing the protocols, dissemination of information, involvement in the ITCC website and lobbying.

More about ITCC can be found at http://www.igr.fr/itcc

ITCC-Consortium
Contact: Marianne Naafs-Wilstra
icccpo@vokk.nl

ICCCPO - news
Childhope

The CHILDHOPE project is a new approach in pediatric cancer treatment since it brings – from bench to bedside (and back) – an innovative technology as yet never applied in children with advanced or refractory haematopoietic malignancies. ICCCPO is one of the partners of Childhope, a translational research project funded by the European Union.

Other partners are Centre Léon Bérard (Fr), Fondazione Matilde Tettamanti e Menotti de Marchi, Università Milano Bicocca (It), The Norwegian Radium Hospital (No), Etablissement Français du Sang (Fr), University College London (UK), Westfälische Wilhelms-Universität Münster (De) and ACIES (Fr).

Leukemias are the most common cancers affecting children while malignant lymphomas – including Non-Hodgkin lymphomas (NHL) – come in third position after brain tumours. A significant number of children with leukemia/lymphomas still fail current therapies. The aim of the CHILDHOPE project is to develop a safe and efficient adoptive immunotherapy for children with advanced or refractory malignancies. CHILDHOPE particularly focuses on three paediatric tumours: Acute B-lineage Lymphoblastic leukaemia, Non-Hodgkin B-lineage lymphoma and Acute Myeloid Leukemia.

The CHILDHOPE translational research project will focus on:

- Improving and testing the efficacy and the safety of anti-leukemia/lymphoma chimaeric T cells in relevant preclinical models in vitro and in vivo in mice.
- Scaling-up this technology to numbers suitable for a clinical application in children with haematopoietic malignancies.
- Based on biological material obtained from preclinical models and from children treated with these genetically engineered T cells, dissecting the interface between the host’s tumour and immune cells and use this knowledge to understand the mechanisms of anti-tumour action, validate novel targets and diagnostic tools specific to children affected with leukemia or lymphomas.

The CHILDHOPE project is built on the excellence of a network of EU-based partners with a broad experience in the field of paediatric haematology and oncology, immunology and cell & gene therapies and integrates the International Confederation of Parents of Children with Cancer and an SME specialised in the project management. ICCCPO’s role lies in the field of ethics and the dissemination of information around ad results of the project. www.childhope.de

Marianne Naafs-Wilstra
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IDA Foundation

IDA Foundation is the world’s largest not-for-profit supplier of essential medicines and medical supplies. IDA supplies quality assured products at the lowest possible price to low–medium income countries. In addition, IDA provides procurement agency services and offers consultancy and training on topics related to pharmaceutical supply management.

IDA Mission statement: To provide high quality essential medicines and medical supplies at the lowest possible price to the not-for-profit sector in low and medium income countries.

IDA Foundation is based in the Netherlands and is ISO 9001:2000, GMP and GDP certified. The quality of IDA products is verified in IDA’s GLP-based laboratories. For more than 30 years IDA has worked out of her headquarters in Amsterdam. The environment in which our customers operate is changing constantly and we feel that IDA needs to change in order to keep abreast of developments, which ultimately should result in better, fully rounded service to our customers. Therefore in January 2005 IDA opened its first regional NGO office: IDA Regional Office Nairobi focusing on Great Lakes and Horn of Africa, i.e. Eritrea, Ethiopia, Kenya, Malawi, Somalia, Sudan, Tanzania, Uganda, Zambia.

Products

IDA Foundation is specialised in providing the pharmaceutical products included in the WHO Essential List of Medicines. In addition, IDA Foundation supplies a range of other items needed in healthcare settings such as medical supplies, laboratory requirements, diagnostic tests and reagents. IDA can supply a lot more medicines and medical supplies. A catalogue on the IDA website gives a complete overview.

More information

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Long term survivors of childhood cancer: cure and care

The Erice Statement

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The number of subjects that have successfully completed treatment for a cancer diagnosed during childhood is increasing over time and entering adulthood.

Members of the International Berlin-Frankfurt-Münster (I-BFM) Early and Late Toxicity Educational Committee (ELTEC) invited 45 pediatric cancer experts (representing oncologists, psychologists, nurses, epidemiologists, parents, and survivors) from 13 European countries (with five additional experts from North America) to Erice, Sicily (from October 27 to 29, 2006) to discuss the circumstances in which the word “cure” should be used when speaking about children with cancer, and when and why continuing follow-up and care may be required. The objective of the gathering was to generate from the personal and professional experience of the participants an overview statement of the group’s philosophy of cure and care of survivors of childhood cancer. The ten points reflect what the group considers essential in the survivors’ cure and care.

The goal of cure and care of childhood cancer

The long-term goal of the cure and care of the child with cancer is that he/she become a resilient, fully functioning, autonomous adult with an optimal health-related quality of life, accepted in the society at the same level of his/her age peers.
The Statement

1. “Cure” refers to cure from the original cancer (see Note below), regardless of any potential for, or presence of, remaining disabilities or side effects of treatment. These side effects are a separate issue needing tailored long-term follow-up based upon subject-specific and treatment-related risk factors. The term “cured” should be used when discussing the survivors’ status with them and in the larger society; vice versa, the term “long-term survivor” should continue to be used in scientific research and related literature to alert professionals to sequelae which require care and attention.

2. The care of the child with cancer should include full and honest information for parents and the child (in an age- and culturally-appropriate manner) regarding the diagnosis of the disease, its management and its curability. The communication of “cure” for an individual child or adolescent and his/her family should occur in the context of an agreed-upon decision taken by the paediatric oncologist in charge, with all persons involved, taking the individual circumstances into consideration.

3. Communication of risk is difficult and challenging. Information about risk should be delivered to survivors and families in language that is easily understood and in a positive light. Effective communication requires a high level of interpersonal skills. Survivors and families have the right to be fully informed in person and in writing about being cured, as well as about the remaining risks of late effects, recurrence of the primary disease or second malignancies where applicable. After completion of treatment for the original cancer, it is the responsibility of the paediatric cancer unit (PCU) to provide the survivor and parents with a summary of the characteristics of the disease, of treatments received, and of complications that may have occurred during therapy. The summary must be combined with suggestions on the type and timing of the follow-up evaluations to monitor the original cancer as well as possible late effects of the disease and its treatment.

4. There is an additional need for continuing systematic follow-up after cure for surveillance of possible long-term effects of the cancer or its treatment. To this end, every PCU should have a well-structured “follow-up clinic” and a multidisciplinary team including one or more of the following: paediatric oncologist, nurse, psychologist, and social worker plus other relevant specialists based on individual patient needs.

5. In order to provide appropriate and definitive advice and support to long term survivors, the PCU needs to collect further information through audit and research. In prioritizing a research agenda the health care professionals should collaborate with survivors and their families. Evidence-based counseling requires the collection of research data on which to base recommendations. Results of such research should be linked back to the provider community and to survivors and families, for incorporation into future practice.

6. Systematic efforts should be made during and after cancer treatment to empower the survivors and families by making available age-appropriate information, and strengthening their coping skills and strategies in dealing with their current and future concerns. Most survivors and their families cope well. By reinforcing these adjustment skills and strengthening their coping strategies, they will develop a resilience that will help them to face and overcome, ever more forcefully and confidently, future life challenges. These strategies will be especially important in dealing with the formal transition from active treatment to after-treatment, from after-treatment to long-term care, and from the pediatric to the adult-focused health care system. A specific contact person should be designated to facilitate these transitions.

7. As stated, the majority of the survivors are relatively well adjusted; indeed there is a proportion with extraordinary resilience. However, compared to the general population, some survivors are at an increased risk of developing conditions that need medical, psychological or social care. The health care system must address all these groups. Accordingly, when the survivor enters adulthood, he/she should be referred to an appropriate health care provider who coordinates long term care. If any specific problem arises that might be considered a possible late effect of treatments received during childhood, the survivor should be referred to an appropriate specialist. The PCU should provide the specialist with as comprehensive a medical history of the former patient as possible. The PCU should be available to receive and retain records on the long-term status of former childhood cancer patients.

8. Parents, siblings, and other close family members should always be encouraged to play an active role in the discussion of future plans, and in the design and implementation of psycho-social interventions. In addition, survivors and parents have a useful role to play in sharing information and life skills, helping to empower other survivors and parents, and in the design and implementation of future services. Parents and advocacy groups should be included as active members in the multidisciplinary health care team.

9. The general public needs to be made aware of and accept the reality of the cure of childhood cancer: that significant progress over the past 30 years in the treatment of childhood cancers has resulted in many hundreds of thousands of survivors who are cured and are now completing school, entering adulthood, and living full lives as active members of society. This population increases every year. The
larger society should ensure that survivors have equal access to education, jobs, insurance, and medical care.

Inequalities of current treatment strategies and cure rates, both within and between nations, based largely on differences in socio-economic status and resource allocation, remain a challenge for the international community to address.

NOTE:

It is not possible to provide an exact definition of cure that applies to all cancers. For the purpose of this document, in the context of childhood cancer survivorship, the group agreed on the use of the following concept of cure. Cure after cancer during childhood refers only to the original disease regardless of any potential for, or presence of, disabilities or side effects of treatment. Children who have been treated for cancer can be considered cured when they have reached a time point at which the chance that they will die from their original disease is no greater than that of age peers in the general population of dying from any cause.

For many of the malignant diseases of childhood a patient who survives free of relapse for a certain number of years after diagnosis according to the type of tumor, can be considered cured. The time to cure depends on tumor type, stage, and other biological factors. In general, it is between 2 and 10 years relapse-free since cancer diagnosis. For some other tumors, attempting precision is unreliable because of underlying strong genetic factors involved in the causation of and response to the specific cancer.

List of participants at the Erice workshop:

Epidemiologists: Julianne Byrne (Chair, Ireland), Guido Pastore (Italy), Maria Grazia Valsecchi (Italy), Peter Kaatsch (Germany), Mike M. Hawkins (Birmingham)

Nurses: Faith Gibson (Chair, United Kingdom), Moira Bradwell (United Kingdom), Ulrika Kreicbergs (Sweden), Nelia Langeveld (The Netherlands), Anne Thorvildsen (Norway), Kathleen Ruccione (United States)

Parents: Mark Chesler (Chair, United States), Irina Ban (Serbia), Marianne Nafswilstra (The Netherlands), Maria Pia Serrafero Bonini (Italy), Christine Wandzura (Canada)

Physicians: Giuseppe Masera (Chair, Italy), Ronald D. Barr (Canada), Joern D. Beck (Germany), Jos Bakkerink (The Netherlands), Gabriele Calaminus (Germany), Andreas Feldges (Switzerland), Giulio J. D’Angio (United States), Riccardo Haupt (Italy), Momcilo Jankovic (Italy), Herwig Lackner (Austria), Torsten Langer (Germany), Edina Magyarosy (Hungary), Renée Maurus (Belgium), Luisa Massimo (Italy), Concetta Micalizzi (Italy), Anja Moericcke (Germany), Jacques Otten (Belgium), Pierre Philippet (Belgium), Gregory Reaman (United States), Cor van den Bos (The Netherlands), Anjo J. P. Veerman (The Netherlands)

Psychologists: John J. Spinetta (Chair, United States), Christine Eisler (United Kingdom), Cinzia Favara (Italy), Pilar Gonzalez-Doupe (United Kingdom), Gabriela Medin (Spain), Bob Last (The Netherlands), Pia Massaglia (Italy)

Survivors: Anthony Penn (Chair, United Kingdom), Eva Coenen (The Netherlands), Angelamaria Cometa (Italy), Marieke van de Wetering (The Netherlands)

From a presentation at the ICCPO/SIOP-conference 2006 in Geneva

The Clinic Nanny Project

My colleague and I are members of the psycho-social staff of the Pediatric Neuro-Oncology Program at Vienna University Children’s Hospital.

Nina Gebetsberger is a clinical psychologist. She started working at the hospital as Clinic-Nanny when she was a psychology student. She will tell you about the experiences she had as a clinic nanny working with children with cerebral tumors. My name is Agathe Schwarzinger. I am an art therapist and psychologist and it is my responsibility to co-ordinate the project!

How the project developed

As you all know, children who suffer from cancer have to spend a fairly long time in the hospital to receive their treatment. It is a very difficult time not only for the children, but has a significant impact on the whole family. The children must go through painful procedures and are isolated from every day activities. Games, books or watching television get boring in time. A change that raises their spirits is definitely welcome. In most cases, the parents spend most of the time with their children. Especially when the parents room-in with their children it is important for them to have the chance to take care of their personal needs, rest or run errands.

In order to support families and help them cope with the stress of hospitalization the Clinic Nanny project was started in 2003. It is a volunteer program and it was designed to provide individual care for children suffering from cerebral tumors and their siblings during their leisure time.

We think, that the project is one of a kind, because each Clinic Nanny focuses on just one special child – during the time of the therapy and if wanted, after the treatment has stopped. The individual care takes place...
during their stay at the hospital. Depending on the family’s needs it is also possible for the CN to make house visits. In this regard, it is very important to us that they meet on a regular and continuous basis, because that’s the only way to build up a trustful and close relationship.

**What kind of service does a Clinic Nanny provide?**

The Clinic Nanny offers support to both children and their parents.
- She promotes the child’s interpersonal skills and helps to minimize the effects of isolation, which can arise during long periods of hospitalisation
- She promotes age-appropriate social and emotional development
- She provides support to the families
- She helps alleviate stress and psychological strain and gives the relatives a chance to rest
- She helps with organisational problems – like keeping up appointments.

It is important to mention that CN are not babysitters! They offer an individual care of the child and should build up a relationship!

**The present situation:**

In Vienna there are 14 Clinic Nannies working with families. All of them are volunteers. The liability insurance is covered by the Austrian Parents Cancer Association.

**Steps in the process**

First we try to identify eligible families. We want to send our Clinic Nannies to the families who need them most. During our multi-disciplinary staff meetings we evaluate the children and their families.

**Criteria for choosing families are as follows:**

- We take families who don’t live in Vienna into consideration since they usually don’t have relatives and friends nearby to help with the care.
- The number and ages of the children in the family are important factors. Families with several children have often problems to meet the needs of the healthy siblings.
- The employment situation is also an important fact to consider. Working parents need more support since they can not be with their child as often as other parents.
- We take single parents into account because they are not able to take turns in caring for the child.
- The emotional pressure on the family is also looked at, as well as, the kind of treatment, the medical prognosis and estimated length of therapy.

In one in one- interviews we inform the parents about the project. If they want to take part in the program we try to select a Clinic Nanny that suits the child and is in the best interest of the family.

**Meeting the families**

I always accompany the perspective Clinic Nanny during the first visit to the child. Together we play with the child so that the child gets to know the Clinic Nanny. I am also there to answer organisational questions that may arise.

The time and frequency of the next meetings are set up between the families and the Clinic Nanny. Some families decide to meet on a regular basic. Others prefer a more flexible solution. - We try to find the best alternative for the family. The parents are present in the beginning, especially when the children are toddlers. This gives the child the chance to get used to the new person and the parents can gain confidence in the Clinic Nanny. When the child and the parents feel comfortable it is possible for the parents to leave. This is an individual decision left up to the family and varies from family to family.

**Clinic Nannies**

The following requirements are necessary to become a Clinic-Nanny:

- Emphasis is placed on the fact, that a young person, who wants to become a Clinic Nanny should have experience and especially enjoy working with children.
- Additionally, it is important, that the Clinic Nanny has knowledge in the field of psychology or education. Therefore most of our Clinic-Nannies are young people who study psychology, pedagogy or medicine.
- Another important aspect is the fact a future Clinic Nanny has to be aware of is that the volunteer work will claim quite a lot of her free time and she must be willing to commit her/himself for at least a year.

**The way to become a Clinic-Nanny**

Applicants must send in a written curriculum vitae. They are then invited to a personal interview that ensures that he or she is qualified for the challenge.

Before they start to work they receive theoretical and practical training. During their theoretical training the CN are given psychological and medical manuals and handouts. The topics range from the impact of illness and hospital on children, how children view health and sickness, crisis intervention and more....These subjects are discussed with the psychosocial staff. In the practical training the CN gets to know the ward and the team. They are given guidelines regarding hygiene in health care settings. It is important for them to learn what to do when they visit children who are in isolation.

Once they start to work in the field they have a close exchange with the psycho-social team. The following points are very important to us.

- We offer continuous supervision and educational training.
- the CN takes part in the psychosocial staff meetings
- if a CN has a question about her child or it’s situation, it is always possible to contact a member of the psychosocial team.
The Evaluation of the Clinic Nanny Project

Last year we evaluated the Clinic Nanny Project in order to see if the clients were satisfied and to receive suggestions for improvements from the families. A questionnaire was developed.

One of the first questions was:
- “What were your expectations for the CN-Project?”

The answers were:
- to get relief from every day chores in the hospital,
- which means more relaxation for the child and their families in the hospital
- there is someone who takes care of the sick child, so the parents are able to spend some time with their healthy children.
- that the children are offered distraction from their illness.

We also asked, if those expectations were fulfilled. It appeared that the expectations were met or even exceeded.

Another question was: “What kind of benefits did you have because of your CN?”
- it was possible to go shopping or take care of the household
- more leisure time for the parents
- more time for the siblings
- distraction for the child
- we were able to go for a walk
- it makes the hospital stay easier
- contact person for the parents
- mental support for the parents
- friendship

We also asked if there were any disadvantages. The parents negated.

We asked the parents: “What qualities should your CN have?”
- She/he should have experience with children
- knowledge of psychology
- be young - a supplement to grandparents

We also wanted to know, what the parents would tell other concerned families.

They said:
- the CN Project is a great possibility to support families in difficult situations
- one should take the advantage of getting a CN. It helps you get some privacy and have time for relaxation
- a CN supports and supplements a family in an ideal way

As you can tell, the feedback was very positive. The children enjoyed the fact that there was one special person, who took time for them. Even if the CN’s primary focus was on the child, we realised, that the CN also became a very important person for the parents as well in some cases friendships were established.

We also asked the CNs for their opinion. Here is a personal summary:

Nina’s experience:
It was a one of a kind experience for me. On the one hand, I had the chance to see if I could work in the field of children with cancer, on the other hand, I developed an intimate relationship with a family. The little girl that I took care of had finished her treatment and was no longer hospitalised. Unfortunately, the side effects were devastating for her and her family. She suffered severe pain and was therefore unable to attend school. In addition she had to be fed via a feeding tube and had problems walking. Nobody could predicts if the situation would get any better and therefore, the whole family was emotionally stressed. The family no longer had the emotionally supporting environment of the hospital to help them. The Clinic Nanny project made it possible to offer the family support in their home. I visited the family once or twice a week and took part in their family life. We shared meals and I played games with the girl and her brother. I talked to the mother. She could take a bath, go shopping or just have time for herself while I was there. I visited the family for 2 years and a trustful relationship was built up. It was a good feeling to know that I was helping a family that really needed support. It wasn’t easy for me and it was time consuming. It took me an hour to get there and an hour to get home. And of course there was the emotional strain involved. I am, however, grateful that I had the chance to have this experience. Now, I am better able to understand what families go through when they are home. Last but not least, it was this experience that made me realize that I wanted to work in this field.

Summary:
The CN-Project has been going on for three years and we can say, that the CNies are an important part of the psycho-social team. The advantage is, as the evaluation showed, that the individual care is great support for the families. Unfortunately, we don’t have enough volunteers, to have a CN for every family. Therefore, we offer a daily entertainment program for our patients in hospital: We have a painting studio, music afternoons, play groups, movies and a lot more.

Basically the concept proved itself and was even transferred to another clinic in Vienna. Finally, we would like to give our special thanks to our Parent Initiative “Kinderkrebshilfe” for the financial support.

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Greetings from the Survivor Network

Just a few quick reminders:

- We would love to hear from any survivor groups we don’t already hear from about developments in their country, or from anyone who is thinking of starting/wanting to develop a group and needs some advice from others who have been in your position.
- We would love to see survivors who are leaders in the survivor network in their own country, or who are leading the development of a group at the conference in Mumbai at the end of September.
- I would love to hear from anyone who believes that they have a suitable presentation topic for the survivor network sessions in Mumbai.

Prudence Walker-Cuttance
Chairperson
International Childhood Cancer Survivor Network
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Peer support helps cancer survivors

A new study, published in the December 15th, 2006 issue of CANCER reveals that the population of 15-29 year-old cancer survivors, feel that socially connecting with other cancer-afflicted peers of the same age can be more beneficial than receiving support from family and friends – contrary to what their doctors believe. Adolescent and young adult cancer patients rank support from family, friends and other cancer survivors as high priority in their healthcare needs.

Researchers from the University of Southern California conducted a comprehensive survey with oncologists, psychologists, nurses, social workers and young adult cancer survivors to better characterise the needs of this patient population and rank them in terms of importance. According to lead author Dr. Brad Zabrack: “Health professionals and survivors value highly the support of family and friends. However, meeting other young people who share a common experience becomes an opportunity for young adult cancer patients and survivors to address common concerns, such as coping with uncertainty about one’s health and future, feelings of being alone and isolated, body changes, sexuality and intimacy, dating and relationships, and employment issues.”

The study also found that this particular population prefers to be treated by physicians who are sensitive to their age-specific needs. They want to see doctors who understand what is important to a young adult at this stage of life – intuitively know how they think and act and, as a result, prescribe treatments best suited for them. Other high priority health and supportive care needs reported by health professionals and young adult survivors were having adequate health insurance and ongoing surveillance and assessment of long-term effects of treatment.

Despite dramatic improvements in childhood cancer survival rates, studies show the incidence of cancer in adolescents and young adults has actually risen higher than in children and older adult patients. Moreover, the improvement in five-year survival for this population has been poorer than average.

Scientists propose that dramatic physical, psychological and social changes that occur during adolescence may contribute to the different outcomes. Therefore, understanding the unique treatment needs of adolescents and young adults with cancer may yield better understanding of cancer management. “These findings provide oncology professionals and young adult cancer survivors with insight into each others’ values and perspectives,” conclude the authors.

They add that the study also points to a need for more age-appropriate educational materials written in a way that makes sense and has meaning for adolescents and young adults.

Source: “Assessing the Health Care Needs of Adolescent and Young Adult Cancer Patients and Survivors.” CANCER; Published Online: November 13, 2006 (DOI: 10.1002/cncr.22338)
Print Issue Date: December 15, 2006
Meeting in Bali

The ICCCPO Asia Regional Meeting was held in Bali, Indonesia on 5-7 April 2007. There were 97 participants with 22 from 12 countries other than Indonesia and 75 from 10 cities in Indonesia.

The theme of the meeting was “Keep Hope Alive Together” and the meeting provided an invaluable opportunity for all participants to share their experiences, knowledge and discuss challenges that they are all facing, from the diversity of speakers including parent groups, survivors, nurses and doctors.

There were several participants attending ICCCPO event for the first time, including Pakistan, Malaysia, Turkey, and Vietnam. Those non-ICCCPO member participants from Vietnam, Malaysia, and Jordan showed great interest to the ICCCPO event and hopefully one day they would become ICCCPO members.

For Indonesians, it was an “ice breaking” and for the first time doctors, nurses, parents, survivors, psychologists from 15 centres all over Indonesia had the opportunity to touch base on many issues of childhood cancer from different perspective. This Meeting had given a new perspective and ideas to some centres to improve themselves. The need to have more meetings together among parents, doctors, nurses, survivors is demanded.

Another encouraging outcome is that - inspired by the meeting - the participants from Makassar and Bali of Indonesia showed the intention to set up parent groups.

The pre-meeting activity in Bali was organized on 26 March 2007 by the local organizing committee on behalf of ICCCPO as Bali has only 1 government general hospital and yet no pediatric oncology ward. It is still believed in Bali that childhood cancer is incurable and children with cancer have no chance to survive. On behalf of ICCCPO, the organizing committee offered to organize a public awareness event to the community on 26 March 2007. About 290 participants consisting of parents, doctors, nurses, primary care-givers, social workers, were attending a public awareness day with a theme “Childhood cancer is curable if detected early”.

A Meet & Greet cocktail party was held at the pool near the beach at the Patra Hotel coffee shop, a very relaxing atmosphere with some participants wearing their own traditional costumes. There was free entertainment from voluntary singers among the participants. Also a traditional Balinese dinner was held at Café Lotus in Ubud Village, a well-known village with many paint- ers and art-shops. ICCCPO participants enjoyed very much the 80 minutes BARONG Dance show on a magnificent stage.

There were many people and organizations supported in different ways to make this wonderful meeting happen. Besides the tremendous effort of some parents, doctors and volunteers, there was great support from Dr. Achmad Hardiman from the Ministry of Health, Governor of Bali, the Dean of Medical Faculty of the University of Bali, Prof. Iskandar Wahidiyat, Prof. Moeslichan MZ and Dr. Djajadiman Gatot. ICCCPO contributed financially with stipends to Asian participants from developing countries and local parents; the pharmaceutical companies sponsored doctors to attend the meeting. The Ministry of Culture & Tourism and Coordinator Ministries for Social Welfare sponsored the Meet & Greet and Dinner!

Last but not least, thanks to everyone in the Organizing Committee, the team-work is excellent.

Ira Soelistyo on behalf of the Organizing Committee
My Second defeat (!)

Cancer has not ceased to haunt me even after having taken away my eleven year old son, whom we lost after eleven months of tiresome efforts to save his life. Indeed, that was the first major catastrophe in my life. As I could not take that tragedy in a normal spirit, I had to take the challenge of fighting that killer-disease Cancer by all possible means. But as ill luck would have it, that resulted in a second defeat. This time, my confrontation was not with the killer-disease cancer. Instead I fell prey to a sort of “mental cancer” infected by the malignancy of some people. My ignominious defeat this time, resulted in losing my profession, my credibility and long-time source of income. The high-rise palace of my 35 year long career as a journalist has suddenly been crumbled. The only cause of such unwanted gesture is the help given to ease the sufferings of children with leukemia which has become the guiding factor of my life philosophy. I spend a lot of time with the unfortunate cancer-children whom I come across with, help them get treatment and supply medicine for them totally free of cost. This is my fight against human sufferings. But surprisingly enough, for such dispensation of service to humanity, I had to be sacrificed on the altar of by mighty opponents infected by “mental cancer.” The assault has come upon me with such malignancy that instead of allowing me any time to defend, all of the sudden, very arbitrarily, they applied a deadly blow so that I tumbled down.

Background of the incident
As a journalist, I joined Daily Ittefaq, a major daily newspaper of our country, as an apprentice reporter in April 1981. In the short span of six months, the management became happy with my competence and appointed me to be a regular staff reporter, later in just 4 years time, I was promoted to be a senior reporter. Subsequently I was given the responsibility of chief of the Chittagong bureau of the newspaper. In the meantime, in 1998, my only son fell prey to the killer disease leukemia (blood cancer). During the 11 months long arduous process of treatment of my sick son, I gathered very pathetic experiences about the horrifying sufferings of blood cancer patients and their misfortune families. Indeed, that prompted me to work for better chances for these patients as much as possible. I set up a voluntary social organization named Children Leukemia Assistance & Support Services (CLASS) in 1999 with the support of similar unfortunate parents of the region. We rendered numerous humanitarian services to over 500 cancer children and their families through this organization during the last eight years. Unfortunately, about 90% of these children have died meanwhile.

Instead of giving a lengthy account of our performance, we will just mention one project which will demonstrate our commitment to cancer children. The first ever Children’s Cancer-ward in the region of Chittagong was set up by the initiative of our organization in the Chittagong Medical College Hospital. I find no difficulty to meet such expenditure from my own income and that of my wife who is a physician. But event though I contributed much time to the proper functioning of CLASS, I never failed to do justice to my profession and even never enjoyed lengthy holiday. Unfortunately, instead of being supported for such worthy activities, I fell victim to the hostile mentality of some persons. Such malignancy may have its root in the fact that CLASS has, in the meantime, achieved a considerable social recognition. Activities of this organization have been given wide coverage by various media. Recently, our activities in observance of the International Childhood Cancer day got lavish coverage in print & electronic media. That might have prompted my management to think that I pass most of my time in working for children with cancer. As such, I was advised to resign from my job within a few days of the observance of International Childhood day 2007. Accordingly I did it.

So I have been defeated again. I lost my job.

Osman Gani Mansur
Chairman, CLASS (Bangladesh)
The 8th Rafi Memorial Painting Competition 2006 was held on Thursday last amidst festive atmosphere. It needs mentioning here that the event is one of the major yearly functions of Children Leukemia Assistance & Support Services (CLASS), the parents’ organization of Cancer –Children. The event was also supported by Rotary & Rotaract Clubs of Chittagong zone.

This year’s competition was wide-spread taken part by over 8 (eight) hundred school students drawn from fifty-two schools of the Chittagong region. An extraordinary aspect of aforementioned competition was that it was participated by a number of Cancer stuck Children.

From 3 pm to 6 pm Safa Arcade Auditorium, the Venue of the competition, was featured by enthusiastic presence of young participants, their guardians & jubilant family members.

Mr. Dhali al Mamoon, professor of fine arts department, Chittagong University, the prime seat of learning in this region & a celebrated painter, was the Chief Judge (Chief of selection committee) on the occasion. Mr. M. A. Salam, a leading patron of CLASS & a renowned social worker, graced the occasion as chief guest & distributed the prizes.

It needs mentioning here that Rafi died of Cancer 8 years back after a prolonged treatment of 11 months in Singapore & India.
Pediatric Oncology Training in Pakistan

As a representative of the Senior Expert Service (Bonn, Germany) I had the opportunity to work 8 weeks in Lahore, Pakistan. It was a challenge to work in the Number one cancer institution of Pakistan, the Shaukat Khanum Memorial Cancer Hospital & Research Centre, which has been certified in 2003 as an Associate Member of the International Network for Cancer Treatment and Research. I was, in particular, impressed how this institution is kept up by donations, and that over 70% of the patients (including many from Afghanistan) are treated free of charge.

As a visiting consultant to the Department of Paediatric Oncology (headed by Dr. Alia Zaidi) I had the opportunity to work with the junior staff in the Outpatient clinic (seeing up to 46 patients a day), also in the 30-bed Inpatient Ward (shared with the Adult Oncology Department), and in the 10-bed paediatric chemobay where the chemotherapy is provided. With 250 – 300 new cancer patients every year this Paediatric Oncology Department was the largest I have seen in my professional career. And I was never before confronted with such a large number of advanced cases, e.g. in bone and brain tumors, retinoblastoma’s, sarcomas, Hodgkin’s and Non-Hodgkin’s lymphomas and leukaemia’s.

A need for more institutions like the SKMCH in this country is clearly established. I also saw many cured patients, but also desperate cases (the tears, the sorrow and the pain are the same all over the world in Paediatric Oncology).

I was very impressed by the enormous manpower of this institution (over 1,000 employees) and the ample space for research laboratories on the third floor. The high technical standard of all the equipment (CT, MRI, FC, CLINAC, DNA-Sequencer, PCR-Systems, the hundreds of computers etc.) should also be mentioned. Also the Hospital Information System on-line (including CT and X-ray images). Patient management and therapy application including supportive care are absolutely up to the state-of-the-art, following the newest European and U.K. protocols. The SKMCH doctors were not only highly qualified and competent, but also very caring and sympathetic with their patients.

Teaching and Training in the Department was excellent. I was happy to contribute with a few lectures on Childhood Leukaemia: Cells, Genes, and Therapies; Genetic Aberrations in Leukaemia Cells; The German Childhood Cancer Registry; Protocol Review. Now, what could be improved?

1. As treatment of children with cancer begins with an absolute requirement for the correct diagnosis (including subtypes), the cellular diagnostics should be supplemented by Cyto- and Molecular Genetics (I left laboratory guide lines for conventional cytogenetics and FISH with Dr. Usman). Furthermore, tumormarkers like MYCN-amplification is an absolute must for risk-adapted treatment in neuroblastoma.

2. I wonder if it could be possible to train the paediatric oncologists in cytomorphology, especially in doing the microscopic bone marrow readings of their patients themselves in order to prevent delay of starting the chemotherapy.

3. Participation of this outstanding institution in international mulicentre, prospective, randomized trials will be the option for the future. Not only the staff will profit but also the patients will obtain the world-wide best. In Paediatric Oncology there is already a world-wide trial (EURAMOS) for osteosarcomas and an Intercontinental Randomized Trial for the Management of Childhood Acute Lymphoblastic Leukaemia (ALL-IC-BFM 2002).

Highlights of my stay were the hospitality and the friendliness of the people in the hospital. My only “low-light” was, being run over by a motorcycle, however, no broken bones, only bruises.

Fritz Lampert, M.D.
Gießen (Germany)
Norway

Fundraising for Children in Cameroon

In Norway most children with Wilms Tumour survive, because of proper care and access to medicine. In Cameroon most children who get this type of cancer die, because of lack of the same!

In Norway the International Childhood Cancer Day (ICCD) was marked on February 10. This year the Society for the Support of Children with Cancer (in Norwegian SKB) wanted to focus on children with cancer in Africa. We got in touch with professor Peter Hesseling, former leader of the children’s clinic at the Stellenbosch Hospital in South-Africa, who is about to start a project in Cameroon, in cooperation with the Cameroon Baptist Convention. He wants to educate the medical staff in local hospitals, and with simple means and cheap medicine, he claims, that this program will prevent many kids from dying of cancer. This project can also provide a standard for other developing countries in the future.

Hesseling has earlier succeeded with similar programs in Malawi, Namibia and Ghana and presented his results at the SIOP conference in Geneva last autumn.

Professor and specialist of pediatric cancer Sverre O. Lie from Norway is also taking part in the Cameroon project.

To put the project into practice, Hesseling and his team needs money. SKB has already donated 50.000,- Nkr, and many local groups gave their contribution from fundraising on ICCD.
Russia: St. Petersburg

We will meet again!

In May, 2005, an international meeting of teenagers (cancer survivors) was held in Estonia. The Estonian Association of parents of cancer children invited teenagers from the Baltic countries, Finland and Russia to the camp. Survivors (13-17 years old) met in a fine place under the name "Klooga Camp" and very fast have got acquainted and made friends with each other.

One year had passed... In the morning of August, 25th, 2006 participants of the second international meeting of cancer survivors arrived in Saint-Petersburg.

The program of the meeting started with the presentation of the participants' homelands.

Children from Saint-Petersburg as a home team set the example for the others. Then Finnish participants took an initiative being followed by teenagers from Lithuania and girls from Latvia. Afterwards we continued to introduce each other in person. Then all participants were divided into several international groups to play team games. There was a lack of translators, but children managed to use all possible and impossible means of communication. In short, it was fun!

One of the tasks was to make the longest "rope" out of pieces of clothes they were wearing. After listening to the task, participants seemed to be confused for a minute, but soon solutions were found, and every piece was put to use: T-shirts, sneakers, jackets, badges, watches, wallets, necklaces, summer slippers, rings ... Everybody enjoyed it!

In the evening the adults gathered to discuss the events of the first day and to exchange impressions. Certainly, we kept thinking about teenagers and their plans for the evening. And what a surprise it was when we found out that they got together in one room to chat.

The next morning we decided to receive more information about their "evening party" and how they had rubbed shoulders with each other. It turned out to be true: in fact they had been talking up to late night, all of them in one room. «What language did you use? » - we were puzzled. «Five (languages)! » - the teenagers responded.

We were glad that from the first day boys and girls from four different countries were able to find a common language.

The second day began with visiting a swimming pool. Then everybody went to the museum "Penates". After dinner the most difficult part of the meeting was scheduled: discussion groups. It had been prepared by our Finnish colleagues. They have been carrying out that activity for several years already, but for us it was the first experience of that kind. Teenagers formed several groups, and received the same task. They had to think about their
future. But at first it was necessary to clarify their attitude to the present situation and to the cancer (disease) they had survived from. At first children tried to joke and laugh. But moving from one task to another their frivolous moods were disappearing, and boys and girls started to reflect on themselves and their future. “Here I am – in a year, two, three years. And in five years – who am I? And ten years later? What will happen to me?”

At the end everybody was asked to write a letter to him/her self after ten years. The youngsters were captivated by the task and scribbled messages with high concentration and excitement. And for “dessert” our Finnish colleagues offered to play all-prize lottery.

In the evening we summed up and congratulated each other for the successful carrying out of the second international meeting. There were a lot of warm words and gifts. «We certainly should meet again!» – participants spoke. In conclusion we offered to leave memories on a long paper roll and soon it was covered with drawings, warm words, wishes and messages.

We will ALL TOGETHER meet again in Finland!

Katerina Kiseleva
Executive Director, CAPAC
St. Petersburg (Russia)

Journal for families of children with cancer established in Russia

Our Russian voluntary organization (NGO) ‘Children and Parents against Cancer’ (Saint-Petersburg, Russia) started to publish a monthly information leaflet ‘Hello!’ in 2001. However limited size of the leaflet does not allow us to highlight all vital problems and the necessary information for the members of the organization and other interested parties. Having studied the experience of our foreign colleagues we came to the conclusion that it will be more effective to publish our own journal. This way we can inform and help families of children with cancer to solve their medical, psychological and legal problems. Further more, we intended to include materials for raising the spirits of the children and their relatives, which is very important for recovery. The main purpose of this project is to give good information to our target groups: families of children who have had cancer or who are in treatment now, parental and charity organization, specialists in different spheres who deal with pediatric oncology and the interested public.

We were able to publish the first issue of the journal ‘Together’ in January 2007 thanks to the financial support within the framework of the Support Program for Socially Significant Activities of Non-for-Profit Organizations ‘Charity Run – Rally of White Nights’ conducted by CAF (Charity Aids Foundation) and also with financial support of Charity Fund ‘Happy World’. The edition of 1000 copies was distributed among families who participate in RVO ‘Children and Parents against Cancer’, in hospitals of Saint-Petersburg where children are being treated. We also have made a direct mailing to parent and charity organization, hospitals and medical organization of Russia and countries of the former USSR: Ukraine, Estonia, Lithuania, Latvia, Armenia, Belarus.

A conference devoted to the establishment of the journal ‘Together’ took place on February, 12 2007 at the information centre ITAR-TASS. The press conference was timed for the International Childhood Cancer Day (ICCD) which is traditionally celebrated all over the world on February, 15th.

This project is really unique as all countries of the former USSR do not have anything of that kind, whereas nearly all parent organizations in other countries of the world have their own journal. We hope that our journal ‘Together’ help to end the lack of information for parents whose children suffer from cancer in Russia. It will be one more step for improving life quality of families with sick children.

Now we start working on the second issue. The position-finding layout of the third issue has been prepared already.

Olga Semenova
Anastasiya Gulyaeva

Regional Group Reports
A very interesting poster was designed in Serbia. It says: "Look at me!"

Ribbons were presented in India.
Announcements

29. June 2007
III. Regional Meeting of Childhood Cancer Parent Organizations
SARAJEVO (Bosnia & Herzegovina)

August 17-19, 2007
2nd Meeting of Parent Organizations in Russia, St. Petersburg

October 29 – November 3, 2007
SIOP and ICCCPO
39th Congress of the International Society of Paediatric Oncology
Mumbai, India
Early Registration Deadline is February 15, 2006 at www.siop.nl
More details: www.siop2007.in
Local Organization Committee: bharatagarwal@iapindia.org
SIOP: secretariat@siop.nl

November 15 -17, 2007
19th Asia Pacific Cancer Conference
Tehran, Iran
If you are interested, contact: info@apcc-2007.org
www.apcc-2007.org

World Oncology Camp 2007
Sponsored by the American Cancer Society (Great Lakes Division) and the YMCA of Greater Toledo, international camp activities are offered to patients (ages 12-16).
Where: Jackson, Michigan (USA)
When: June 2007.
There are also plans for an international young adult’s camp (ages 16 –20).

If you are interested, contact:
Vicki Rakowski (Exec. Vice President) at: Vicki.Rakowski@cancer.org

FIRST ANNOUNCEMENT

May 24. 2008
International Open Symposium on Childhood Cancer Survivorship:
“Care and Cure for All Children and Survivors of Childhood Cancer around the World”
Tokyo, Japan
For information contact:
Asian Children’s League Japan
Ms. Kazuyo Watanabe
1-36-9-601 Nihonbashi kakigaracho, Chuo-ku,
Tokyo, Japan
+81 3 3663-1369, Email: accl@accl.jp

February 26-28, 2008
SIOP Asia-2008
In Quest of a complete cure in Muscaat, Sultanate of Oman
More information: www.siop.nl

October 1-6, 2008
SIOP and ICCCPO
40th Congress of the International Society of Paediatric Oncology
Berlin, Germany
More details: www.siop2008.de
Local Organization Committee: siop2008l@charite.de
SIOP: secretariat@siop.nl
29. June 2007 Sarajevo (Bosnia & Herzegovina)
III. Regional Meeting of Childhood Cancer
Parent Organizations in Countries of the former
Yugoslavia

28. June - Arrival
18:00 at the hotel “GRAND”
19:00 dinner at the hotel “GRAND”

29. June - Conference at the hotel “GRAND”
09:30 Opening
Sanjin Beciragic – board member of “Srce za djecu...” – Sarajevo
ICCCPO representative – Simon ?
ICCCPO representative – Anita Keinesberger
ICCCPO representative – Irina Ban
10:00 “Turnover” – brief reports by:
Macedonia
Slovenia
Croatia – Zagreb
Croatia – Split
Croatia – Cakovec
Serbia + Republic Srpska
Bosnia
11:15 Dr Edo Hasanbegovic - The Head of Hemato-oncological Department
General manager of the Children’s hospital in Sarajevo
11:30 Prime Minister – BiH
Minister of Health – BiH
Other government authorities of BiH
11:45–12:00 Coffee
12:00 Interactive session: Managing of the parent organization
12:45 Interactive session: Volunteers
13:45–14:45 Lunch
14:45 Program to be announced
18:00 Visit the old city of Sarajevo “Bascarsija”
19:30 Dinner

30. June
09:30 Visit the Hospital and new office of the association “Srce za djecu....”

Departure

August 17-19, 2007, St. Petersburg
Preliminary Schedule for the 2nd Meeting
of Parent Organizations in Russia

Friday, August, 17
The participants arrive.
Registration of the participants.
Meet and Greet evening.

Saturday, August, 18
Session 1
09.00 – 09.10 Opening ceremony.
09.10 – 09.20 Speech of welcome of the ICCCPO representa-tive
09.20 – 10.30 Introduction of the participants of the meet-ing (2-3 minutes)
11.10 – 11.40 Report of the psychologist “Psychological aspects of the work with family of cancer child” (parents, grandparents, siblings), Facilitator: Dr. I. Shatz
11.40 – 12.00 Discussion, exchange of experience, ques-tions.
12.00 – 13.00 Lunch

Session 2
13.00 – 13.40 How to create the parents’ organization. Planning of the targets and activity of the organization. Facilitator: K. Kisseleva, Russia
14.30 – 15.10 The importance of PR-activity of the non-profit organization. Facilitator: PR-manager
15.10 – 15.30 Discussion
15.30 – 16.00 Coffee-break

Session 3
17.40 – 17.50 Summarizing of the Meeting. Facilitator: K. Kisseleva-Russia
17.50 – 18.00 Closed session of the 2nd Regional Meeting.
20.00 – 23.00 Farewell dinner

Sunday, August, 19
10.00 – 13.00 Excursion. Departure of the participants. Organizational committee: K. Kisseleva, Russia, S. Shut, Ukraine
Theresa Lloyd:

**Why Rich People Give**

(Association of charitable foundations, 2004)

Everyone who seeks partnerships with the wealthy and wishes to see a strengthening of their commitment... should read this book. Lord Joel Joffe

“Why Rich People Give” is the result of the first major research into the attitudes of wealthy people in the UK to money - how they create it, keep it and spend it. The book provides an in-depth analysis of the motivations of the rich to support the charitable sector - or not - by giving money, time and expertise. It covers attitudes to faith, family and community, early experiences of giving and motivations, incentives and rewards. It examines relationships with recipient charities, how people give and feelings about wealth and responsibility. The research provides invaluable insights into the perceptions of wealth in the media, the experiences of fundraisers and others in asking wealthy people for money, and the views of professionals such as lawyers and accountants offering them advice. It considers how UK major philanthropy compares to the US and concludes with an enlightening analysis of the implications of the findings and key recommendations.

Why Rich People Give is essential reading for all charities, organisations and institutions aiming to improve the effectiveness of their relationships with major donors, and for those wishing to strengthen the culture and practice of giving among people with substantial means.

**About the author:**

Theresa Lloyd is a leading consultant in strategic planning, fundraising and governance for the non-profit sector and also advises families on the development of their philanthropic strategy. She was Director of the Philanthropy UK project, a 3-year initiative set up in 2001, and is now a member of the Philanthropy UK Advisory Board. She wrote the first edition of *A Guide to Giving* in 2003. Theresa can be reached at [www.theresalloyd.co.uk](http://www.theresalloyd.co.uk).

How to order:

*Why Rich People Give*


ISBN 1 897916 11 6

Copies can be ordered for £15 plus p&p through the Directory of Social Change: [www.philanthropyuk.org/why_rich_people_give.asp](http://www.philanthropyuk.org/why_rich_people_give.asp)

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CLIC Sargent recently published

**Chemotherapy, Cakes and Cancer.**

An A-Z for living with childhood cancer

The book was written by 14-year-old Megan Blunt, who was diagnoses with osteosarcoma when she was twelve. She wrote it because she could not find any material in the UK suitable for children her age.

“Chemotherapy, Cakes & Cancer” is available free of charge through treatment centres in the UK. If you like some copies of the English version contact CLIC Sargent or download your free version: [www.clicsargent.org.uk/Publicationsandresources/CLICSargentpublications](http://www.clicsargent.org.uk/Publicationsandresources/CLICSargentpublications)

Cassie Davis

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**Donation in memory of Naoki Kojima**

Mr and Mrs Kojima, both member of the Childhood Cancer Association of Japan, have donated 1.000.000 ¥ (the equivalent of 6.312) to ICCPO to commemorate their son Naoki’s 21st birthday, in Japan an important event called “Coming of Age”.

His mother, Shizue, whom many of you may know from the ICCPO conferences, writes the following:

“It is nice to share our feelings toward our son Naoki with other parents and families who have experienced similar loss. I believe most of the parents who lost their child will live with the sorrowful experience and the memories of the child, days, and moments spent with the lost child, rather they would count the ages of the child and imagine how s/he would grow up to be.

When Naoki left us, he was 10 years old and in the fourth grade of the elementary school. Ten years from then has a special meaning for us. He would have celebrated Coming of Age Day this January, and his younger brother will be 20 years old in August this year, which is legal adult age in Japan. Our three boys will be all grown-ups this year.

Naoki is still with us at home, which means we have been keeping his ashes in the urn in the living room. My husband understood my feelings, so he didn’t insist to bury Naoki’s ashes right away. I now think it is the right time for Naoki to leave us, he is old enough to be independent.”

Shizue Kojima
Chair of International Committee of Children’s Cancer Association of Japan

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**LÖSEV**, the Turkish group for leukemia in children, again invites for a week long family gathering in Turkey:

**From May 26 to June 1, 2007**

Participants arrive in Ankara and leave from Antalya.

More details: [www.losev.org.tr](http://www.losev.org.tr)

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**Interesting Websites:**

- [www.childcancure.org.hk/english/about/](http://www.childcancure.org.hk/english/about/)
  (English Website of the Little Life Warriors Society (Hong Kong))
- [www.siop.nl](http://www.siop.nl)
- [www.siop2007.in](http://www.siop2007.in) gives current information on the SIOP-Conference in Mumbai (India)

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For changes of addresses (which occur frequently) please check the website: [www.icccpo.com](http://www.icccpo.com)
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