The President’s Message

This year marks the 10th anniversary of our organisation and one we can be proud of both as parents and as health professionals.

From our humble beginnings in 1994 with a membership of only 5 countries, we have now grown to over 60 countries covering all parts of the globe. However there are so many more we need to reach out to, and we seek your help in this.

We acknowledge the contribution every one of you has made to the parent groups in your own country. Time and energy as well as your expertise are a valuable gift and one which we appreciate greatly.

The ICCCPO mission states that every child shall get access to the best possible treatment available in his/her country.

Twinning becomes invaluable – we are seeing more and more programmes between developed and underdeveloped countries. It is great to see increasing cooperation between countries: The sharing of resources, wealth, information and expertise can only improve the outcome for children who suffer from cancer. These are good initiatives and we acknowledge the generosity of the donating countries.

ICCCPO is also about empowering parents to become a well-informed voice in the treatment of children with cancer. Parents can then form successful lobby groups both at local government and on the international front. I believe ICCCPO is a powerful ally with SIOP in helping raise awareness of the plight of children with cancer. Proof of this was seen during our recent appeal to the United Nations which drew the attention of the IAEA (International Atomic Energy Agency).

With the combined efforts of SIOP and ICCCPO I believe we can secure funding for certain cancer treatments in developing countries.

Furthermore, the latest initiative of SIOP to seek the World Health Organisation’s endorsement for free treatment of ALL cancers is very timely. ICCCPO fully supports this and we will do whatever is in our power to ensure this becomes a reality.

The Parent sessions during this year’s SIOP/ICCCPO-meeting reflect many of these thoughts. It is also a wonderful opportunity to meet with delegates from all these different countries and share experiences as well as ideas.

Simon Lala
Chairman

Celebrating the ICCCPO-meeting with a dinner arranged by the Norwegien group SKB.
The beginning of the international federation in 1994 was celebrated with an international symposium on childhood cancer organized by the Spanish confederation of parent initiatives (ASPANION) in Valencia. It made sense to commemorate the tenth anniversary again with an international symposium. Thus the Spanish confederation invited parents from Spain and speakers from abroad, as well as all present ICCPO board members and those who had been elected to the very first board. Not all could come to attend these two days in May, but for those taking part it was a memorable event and a wonderful opportunity to meet again with
International Childhood Cancer Day

This year's International childhood Cancer Day saw ICCPO appeal to Kofi Annan for help in getting equality in treatment for children with cancer around the world. Under the UN Charter on the Rights of the Child, every child has the right to life, treatment when ill, and rehabilitation.

A UN agency has responded to the appeal and ICCPO along with SIOP are now in dialogue with them to see how the parties can work together in the transfer of knowledge and skills from one country to another. The appeal has also received support from a number of governments around the world.

Many interesting talks were presented at the conference, which clearly demonstrated that much has changed for the better for children with cancer in Spanish hospitals. One very impressive example is the talk by Hortensia Dias Asper at the ICCPO-conference in Oslo (s. p. 4) on the schooling of children in hospital.

The day was concluded with a wonderful dinner at one of the old restaurants in Valencia, where a Thank-you-basket filled with “typical” presents from the board members’ countries was handed over to the hosts.

Cancer Research UK has played a key role in raising the profile of this appeal in the media. TV and media coverage has helped to draw the appeal to the attention of agencies like the UN.

The International Childhood Cancer Day was celebrated in over 30 countries throughout the world. There were organised parties for children in hospitals, conferences, media coverage and fundraising events in support childhood cancer charities, both local and worldwide. A CD covering members events can be obtained by ICCPO members from:

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Jesús M. Gonzales Marin, the driving force in the founding of ICCPO as its first president.

All international delegates were invited to the Valencia townhall where ten years ago the statutes had been signed. This time they were received by the president of the Valencia province and the health minister.

Also part of this delegation was the present president of SLAOP (Society of Pediatric Oncology in Latin America), Dr. Sylvia Brandaalise, who spoke about the situation of pediatric oncology in South America.
A few notes about the birth of the International Society of Pediatric Oncology

In 1959, governments and pediatric societies worldwide realized that leukemia and other malignancies were the main cause of death in children after the first year of life. At that time, few pediatricians were involved in basic research and clinical investigation on these diseases, and few hospital departments were devoted to this specialty. To be sure, the pediatric unit of the Institut Gustave-Roussy in Paris directed by Dr. Odile Schweisguth was one of the pioneering groups in Europe. Being able to count on this expertise, therefore, the Centre International de l’Enfance organized the first advanced course on pediatric leukemia and cancer at its Chateau de Longchamp headquarters in Paris, nominating Dr. Schweisguth as course director. The faculty included several professors from the University of Paris and a few from other countries who were particularly active in this field of pediatrics. Some lectures and the practical work were held with hospitals throughout Paris. Course participants were chosen by their respective governments and provided with a grant; only a few countries were allowed to send two students, since the intention was to create a capacity building cascade effect, i.e., to teach only one per country, whose duty and job it became to return home with the acquired knowledge and to impart this at his/her local and country level. Students came from Belgium, Czechoslovakia, Finland, France, Germany, Holland, Hungary, Iran, Italy, Lebanon, Poland, Portugal, Spain, Sweden, Switzerland, Yugoslavia, UK, USSR, Uruguay, and USA. I had the honor and privilege to be selected as the sole Italian attendee.

At this point in the 1960s the need to work together and to have the opportunity to hold meetings on this new specialty was becoming increasingly felt. Most of us joined the then Cooperative Groups of the European Organization for Research and Treatment of Cancer (EORTC). We were still able to meet in Paris and to visit Odile, who indeed was a beacon for us, and her department. In 1966, Dr. René Maurus from Brussels, a pupil at the first Course held in Paris and totally devoted to pediatric oncology, and I went to see Odile after a meeting of the EORTC where none of the topics concerned children. We appealed to her to use her experience, acquaintances and clout to unite the few pediatricians interested in oncology and to found a working group. Soon afterwards she organized a first meeting in Paris where the Club Européen d’Oncologie Pédiatique was launched. On September 24th and 25th, 1967 I organized the second edition in Tremezzo (Como). Thereafter, we held a few more meetings in Paris, and at last in 1968 consensus was reached to establish an international society named the Société Internationale d’Oncologie Pédiatrique (SIOP). Prof. Monereo, a pediatric surgeon from Madrid, was designated to host the first international congress in 1969. Subsequent events included Lyon (1970), Mainz (1971), Manchester (1972), Amsterdam (1973) and Genova (1974).

From its outset, the SIOP has been very active, attracting hundreds of pediatricians, surgeons, radiotherapists, pathologists, nurses and other health care professionals involved in the care of children with cancer from all over the world to its annual conference and continuously adding to its membership ranks.

In conclusion, since 1969 pediatric researchers and clinicians have benefited from the high-level forum that the SIOP annual meeting provides and the effective exchange of experience that it guarantees. Indeed, many working groups have been created as a result of consensus reached during these events, and many important articles have been published in international journals. Surely, the SIOP has served as a continuous stimulus for all of us, basic and clinical researchers alike.

Having been a part of the society’s birth and early growth is a privilege that I cherish.

Prof. Luisa M. Massimo, MD
Director Emeritus
Department Pediatric Hematology and Oncology
G. Gaslini Scientific Children’s Hospital, Genova, Italy
Gold Medal of the Italian Republic for
Merits in Public Health
The survivors’ meeting – a great success

We are pleased to announce that the annual ICCPO Survivor Meeting held in Oslo, Norway was a great success. This year we had over 30 delegates from across the world, including Austria, Britain, Canada, Germany, Greece, Finland, Japan and New Zealand. The Survivor Executive Committee, made up of six survivor representatives throughout the world, had the opportunity to meet prior to the commencement of the conference at which time they outlined objectives and designed a strategic plan towards achieving the goals and objectives of the ICCPO Survivor group. Throughout the three-day conference delegates attended sessions pertaining to

- How to Set Up a Survivor Group in Your Own Country,
- Supporting Newly Diagnosed Children with Cancer and their Families
- and Fostering Hope in the Face of Adversity.

Prudence Walker, of New Zealand, led an information session on the process involved in establishing and maintaining a survivor’s group in one’s own country. As a follow-up, delegates participated in a sharing session where individual survivors exchanged personal experiences, resources and knowledge gained from creating a Survivor’s Group in their own country. This was an invaluable experience for those individuals who are currently attempting to set up their own group.

The desire to give back to our communities, especially the hospitals that played such a large role in our treatment, appears to be a consistent goal for many of the survivor groups that were represented at this year’s meeting. A session relating to developing and implementing skills required in supporting newly diagnosed children with cancer and their families encouraged delegates to practice their acting skills through role-playing the many ways we can mentor families in various situations. A huge thank you goes out to Michigan University Professor Mark Chesler, parent of a long-term survivor and ICCPO Board member, who provided the resources and knowledge, which made this session a success and allowed us to laugh as well as learn from our unique cancer experiences.

The conference was not all work and no play! Thanks to the phenomenal leadership and organization of Steinar Krey Voll, of the Norwegian Survivor Group, we were spoiled with a trip to three local museums followed by a boat trip to Langoyenne islands in the Oslo fjord. It was on the islands that we played paintball and explored the beautiful landscape of the islands. To top it all off we were treated to a magnificent Norwegian shrimp buffet prior to heading back to our hotels.

Next year’s ICCPO Survivor meeting will be held in Vancouver, British Columbia, Canada. We are very excited about the upcoming meeting. Program planning and ideas are already in the works for next year’s conference. We are looking forward providing an incredible program and quality experience such as the one we had in Norway. With empowerment and energy gained from this year’s meeting, the Survivor Executive Committee is confident about the fun and excitement that awaits us all in Vancouver 2005.

See you in Vancouver!!!

Nicole Bruton
Executive Survivor Committee
ICCCPO Liaison – North American Representative

A quote from the letter of a mother who travelled with her son (a survivor) to Oslo may illustrate the impact such a meeting can have:

“...let me tell you a bit about my son. You saw yourself how depressed the boy was. For eight years I tried to stimulate him in a positive way and hoped to make him more interested in learning and striving for a good future for himself. But he always replied: “Leave me alone, there is no future for me.”

With a lot of difficulties I convinced him to come with me to Oslo to meet with other young survivors. And already after the first day of the meeting he was changed. Now, back home, he is full of energy, he goes to school voluntarily and asked the teacher to teach him more English because he is dreaming of travelling to Vancouver. He helped me to prepare a meeting for other young survivors of our group which was very successful.

I am so grateful that this all happened.”

N.K.
The ICCCP2O Experience

I have gained so much from this experience. Everything from the people I met, to the different sessions I attended, to the guest speakers, is going to be something to remember forever and guide me through the rest of my life.

One of the main things I learned is that there are survivors all over the world, like my survivor group in Canada, trying to make a difference. The survivors that I met at the conference are all on a different walk of life. Some groups were well established, and had set up programs where they were visiting newly diagnosed patients in the hospital. In some countries, if you told people you were a survivor, you put your career in jeopardy.

For me this conference meant the celebration of survivorship, friendship, support and knowledge. I was inspired by new ideas, different ways of overcoming obstacles, and I felt a sense of renewed passion. The group I work with in Canada called "Mentors for Life", have had their fair share of closed doors and disappointments. I now know how to approach and plan some of the projects that we were trying to launch, by talking with some of the members of the ICCCP2O meeting, who have had success in certain areas. I know we can take our dreams farther.

It was easy to build a relationship with people through this connection, because you have a common bond that you share. We hear about one another's stories, our pain, our courage, the fight, drive, and passion we have about what we are trying to accomplish. Sometimes very few words have to be said to feel understood. I met a lot of energized people, and was able to quickly develop relationships that will continue to grow. I look forward to a shared stimulated sense of inspiration that we can provide for each other.

I was happy and eager to share our team's success, for others to learn from. There were many people at the meeting that walked away with new ideas from our group. But, my main goal was to discuss areas where we did not have success. What a great opportunity to get some constructive advice! I heard, and learned from others. I asked as many questions as I could to bring back a clear understanding of what we need to do to accomplish our goals with great success. I was eager to learn about the steps it takes to develop a program to enter into hospitals, how to talk to newly diagnosed patients and to give hope to their families.

I now realize that we need to take a few more baby steps to build a foundation instead of jumping into something unprepared. I will be able to incorporate other programs, involving cancer survivor siblings, into our group.

As a whole, I have been inspired. As a person who wants to change the way people interact with childhood cancer, I can succeed with the strength of others and the community of a caring team.

Carie Wik
Mentors for Life
Canada

Survivors
(for cancer patients)

Have you ever stopped to wonder
Why it's so calm after a storm?
All the evil in the world
Seems to be somehow washed away
The world seems so perfectly right
The way God intended
Sometimes a storm appears in our lives
There seems no way out
We focus on the negatives
And seldom see the positives
But when we do, we find that
The problem can be overcome
We get that zest for life
We appreciate the fit of life more
I believe we, as survivors,
Show those positive signs
We have the will to live
We overcome temporary setbacks
And come out a stronger person
We look forward to the future
We are able to set and achieve goals
It's our positive state of mind that
Makes us survivors.

Craig Caldwell
(South Africa)
Auke Beishuizen

New developments
in drug research in paediatric oncology

Introduction
Within the space of 40 years, childhood cancer has changed from being a fatal disease to being curable in 70% of the cases. Especially, Wilms’ tumours, Hodgkin disease and Acute Lymphoblastic Leukaemia (ALL) show excellent survival rates of 75-95%. For a large part this is due to the introduction of effective (combination) chemotherapy and intensification of treatment. Moreover, improved supportive care, bone marrow transplantation and specific treatment protocols, including radiotherapy and surgery, for each cancer have contributed significantly. Still, nearly one-third of children with cancer dies due to the cancer or to early or late toxic effects of therapy. Therefore, new effective drugs are needed for better survival, less toxic effects of treatment and a better quality of life.

Development of new drugs in paediatric oncology
Nowadays, ~70% of drugs used in children have not been analysed in children. Children are therapeutic orphans. Pharmaceutical industries are not willing to perform drug studies in children from an economic point of view. The market is too small. Furthermore, children need special administrations (suspensions, small tablets).

To address this point, partly due to pressure of parent and patient organisations in the USA, the American Congress has set aside a significant amount of money for the benefit of drug studies in children. Several Research Centres specialised in drug research in children are established in cooperation with University Hospitals. Furthermore in 1998, the National Institute of Health (NIH) issued a policy requiring inclusion of children in “all human subject research conducted or supported by the NIH” unless there are scientific or ethical reasons to exclude them. From 1997 till 2001, the US government attempted to provide financial incentive for pharmaceutical companies for paediatric drug development by introducing the Food and Drug Administration (FDA) Paediatric Exclusivity Provision, which was reauthorised as the Best Pharmaceuticals for Children Act in 2002. This act offered an additional 6-month market exclusivity to existing patents for all formulations of any products that have been examined in children, whether appropriate for paediatric use or not. In addition the FDA Pediatric Rule of 1998 requires evidence from randomised controlled trials before new therapies of indications for existing therapies are approved for use in children. This Rule was challenged in court and struck down on Oct. 17, 2002 on the grounds that it exceeded the FDA’s statutory authority to force pharmaceutical companies to test their drugs in children. The FDA, in response, called for Congressional support. On Nov 19, 2003, the US House of Representatives approved the Pediatric Rule, giving the FDA authority to mandate paediatric studies in specific defined conditions, provided the drug is widely used or is considered a therapeutic advance. As a result of these recent changes in regulations and legislation in the US, more trials have been done on children in the USA in the past five years than in the previous 30 years, with resulting improved safety information as well as dose changes for paediatric describing. There is currently no legislation regarding paediatric licensing in any other country. In December 2000, the European Union Health Council adopted a resolution calling on the European Commission to develop similar incentives in Europe. However, a concrete legislative proposal is still to come from the European Commission.

Methodology of early clinical studies
The methodology of clinical studies describes in the first place laboratory research in which a potential drug is analysed in tumour cell-lines and cultures of tumour cells. The second step is animal experiments. Animals can serve as an in vivo tumour model or as a model for toxicity analysis of the drug. Based on these findings, research in humans can start in several phases. The first phase is finding the maximum tolerable dose (MTD) of a drug. Different cohorts of patients receive an ascending amount of the drug until toxicity is the limiting factor. During these experiments the pharmacodynamics (what the body does to the drug) and pharmacokinetics (what the drug does to the body) are analysed. The MTD of the drug is used in phase II studies. In these studies the response of the tumour, toxicity of the drug and pharmacodynamics and kinetics are analysed. In the case of a fair tumour response the drug will be (randomised) compared in phase III studies with standard treatment.

Nowadays, new (targeted) drugs are only available for children with cancer when these drugs are already analysed in phase I and II studies in adults with cancer and when phase III adult studies are initiated. This means a delay of at least five to ten years before ‘promising’ drugs are available for phase I/II studies in children. This is not acceptable, all the more because the majority of childhood cancers is unique and is not found in adults.
European New Agent Group

A European collaboration, named EURO-New Agent Group (EURO-NAG), has been established between France, England, the Netherlands, Italy and Germany to facilitate phase I/II studies in children with cancer. Since 1996, physicians from France (Vassal) and England (Morland) have initiated 17 phase I/II trials in children with cancer (solid tumours). One year ago, EURO-NAG also started off a laboratory consortium of nine laboratories well known for their experience with biology studies in childhood malignancies and pre-clinical drug evaluation systems such as animal xenografts and cell-lines. This consortium is called Innovative Treatment for Children with Cancer (ITCC). In this consortium new (targeted) drugs can be developed or analysed and selected in pre-clinical setting. So, new drugs will be available more quickly for treatment of childhood cancer. The ITCC has also contacted pharmaceutical companies to collaborate in finding or analysing promising new drugs.

European Legislation

Drug studies in Europe can only be done according to the European law based on the European Directive (2001/20/EC). Since the first of May 2004, this Directive has to be implemented in the local laws of each European country. The main issue of doing research (drug) studies in human beings (children) is the informed consent. The second important point of this Directive is the restriction of non-therapeutic research in incapacitated persons, such as children.

The history of informed consent for research studies in humans goes back to Germany in 1891. The Prussian Minister of Internal Affairs at that time promulgated a directive for all prisons that certain drugs (tuberculin against tuberculosis) must not be used against the explicit will of patients/prisoners. Nine years later in 1900, a Prussian Minister of Medical Affairs founded the first legal base for medical research in humans with informed consent, especially non-therapeutic research. Since 1931, during the Nazi period, all legislation, concerning (non-) therapeutic research in humans, was lifted. During the ‘Nuremberg’ law suits, the informed consent procedure became important again (Code of ‘Nuremberg’, 1946). But, despite the Declaration of Helsinki in 1964, it took several years (till 1969–1972) before special Institutional Review Boards (IRB) in the USA were established to judge research protocols before experiments could be done in man.

In the Netherlands, based on the European Directive, non-therapeutic drug studies in children are only allowed when the scientific results can solely be obtained by research on persons belonging to the category concerned (sectional interest or group restriction). Furthermore, when minimal risk criteria are fulfilled, in which this minimal risk is defined as risk to the child experience during normal life and last but not least when the burden of the research is minimal. The burden of the research conducted in children depends on the kind of investigations and duration of research.

Nowadays, phase I/II studies in children with cancer are often developed to determine the optimal biological effect instead of the maximum tolerated dose of a drug. This is based on less toxic effects of the drug because it is a tumour specific (targeted) drug and it is also based on data of pre-clinical screening models of specific childhood cancers.

Examples of targeted drugs in ALL

The overall survival in ALL is ~80% by effective but non-specific therapies. Therefore, more effective, targeted therapies are needed, especially for high risk ALL with dismal prognosis such as Philadelphia chromosome positive (Ph+) ALL and infant ALL (children with ALL < 1 year of age). ALL are characterised by chromosomal aberrations such as translocations and deletions. In case of translocations leukemogenic fusion products can be found. In Ph+ ALL, a translocation between chromosome 9 and 22 occurs causing a fusion between the two genes abl (chromosome 9) and bcr (chromosome 22). This fusion gene encodes a BCR-ABL fusion product, which has enhanced tyrosine kinase activity causing cell survival. A specific inhibitor STI571 (Glivec®, Gleevec®) against this tyrosine kinase has been found causing cancer cell death in a significant amount of patients giving rise to a better prognosis in Ph+ ALL.

Certain types of ALL, such as infant ALL, are characterised by a high expression of specific genes. Infant ALL are associated with a poor prognosis (Event Free Survival of 35%) and known for their in vitro resistance to cytostatic drugs. In infant ALL, fit3 activation as a consequence of fit3 overexpression is found. This fit3, a tyrosine kinase, is known to be oncogenic in acute myeloid leukaemia (AML). PKC412 appeared to be a potent fit3 inhibitor causing cell death in several in vitro models and in phase I and II studies in adult patients with AML. Phase I/II studies are currently under development in infants with ALL.

Conclusion

Although survival has improved in paediatric oncology, still 30% of children eventually die. European legislation allows non-therapeutic paediatric drug studies when these studies fulfil specific criteria. Targeted drugs in paediatric oncology are needed for specific therapies, especially for childhood cancers with a bad
prognosis. STI571 and PKC412 are examples of target-
ed drug therapy against tumour cells with minor toxic
effects. It is important for progress in treatment of
childhood cancer that phase I/II studies can be done in
children with cancer and with the shortest delay as
possible.

Sincerity and responsibility go hand in hand
and empathy follows. Individuals who are
like-minded and devoted to the cause are the
back-bone of groups
involved in welfare
activities. How to form
a group and how to
develop it? To start with
it is of utmost impor-
tance that the purpose is established. It may start
with one person or a group of persons or as an offshoot of
a bigger group, the basic principles remain the same. A
vision that is shared strongly with focussed results is
the crux of the issue. It is most important to identify
the area of work and then to understand the nature of
the work. A cause that involves compassion, love, sinc-
erity, credibility can only be fulfilled by people who are
involved in doing some good work. For example let us
begin with forming a group of parents of childhood
cancer patients. We know parents can only wish the
best for their children and can empathize very well
with other parents. They feel the same pain, share the
same trauma, experience similar difficulties and to top
it all they want to do their best to reduce the agony
and trauma related to the disease. The bond is some-
times so strong that even blood relatives and friends
are left behind. Such a group can definitely alleviate
and reduce the agony by sharing each other’s experi-
ence.

Well sometimes, especially in the case of developing
countries it has been observed that due to overbearing
expenditure involved in the treatment, the inconven-
iences experienced due to distances, non-availability
of specialists, poverty, illiteracy, superstitions, low con-
fidence level and above all the fear of being singled
out by society prevents parents to go ahead and form
a group. In India, people still want to hide the disease,
they still live in a world where there is more faith in
miracles than medicines, where parents are unaware
and discontinue treatment due to numerous reasons.
Here comes a group that comprises of social workers,
siblings, survivors and of course some enterprising par-
ents. In my kind of countries, the role of social workers
who are compassionate, educated, aware and
extremely genuine is like a pillar that supports the
creeper. These groups not only provide the much need-
ed emotional and financial assistance but also provide
a platform for the parents to interact and give them
the confidence first to cope and then to help. Whether
it is a parent group or a group of sensitive citizens the
aim is to make it as useful as possible. A group can
develop and function well if we keep these few points
in mind.

The group activities must be (a) transparent,
(b) result-orientated, (c) practical, (d) consistent,
(e) interesting.

Some rules
- Group responsibilities should be shared with each
  member allowed to function in his/her areas of
  choice.
- Regular meetings and maintenance of records are
  essential.
- To avoid stagnation, new areas of interest related
to cause should be created. This could create more
  space for new volunteers.
- Let the group function under various subgroups to
  reduce friction and create harmony.
- Dinner meetings or similar gatherings of group
  members and their families strengthens the bond.
- Individual talents and resources to be tapped
effectively.
- To enable the group to be more credible and con-
sistent it is important to follow certain do’s.
- Doctors associated with the disease to form an
  integral part of the group.
- Regular interactions with other welfare groups.
- Associating some local celebrities with the group.
- Involvement of local schools (children are the best
type of volunteers).
- Stay away from politics as far as possible.
- Engage the press for all major activities.

Go international: Experiences shared by people
from different backgrounds is learning experience
which cannot be substituted. Helps the group to
develop tremendously.

This talk was presented at ICCPPO-meeting in Barretstown, 2003
Aaradhna Mittal, Sahayta, India
Home Care of Pediatric Oncology Patients
A report on experiences of a pediatric oncology unit in Germany

The following is a presentation of a project at the department of pediatric Hematology/Oncology in Bonn, Germany, which was started – and at the beginning solely funded – by the local parent initiative. It is not the only such project in Germany but, since home care for children with cancer is not generally covered by the health insurances, there are not many services of this kind.

In Germany, approximately 1,800 children under the age of 16 are diagnosed annually with cancer. If we include the 16 to 18 year old patients the figure is approximately 2000 to 2200 per year.

Advances in the treatment of childhood cancer have dramatically increased the survival rate. Today, the 15–year overall survival rate is about 70% for all malignancies in childhood. On the other hand, there are still approximately 500 children per year who die from the disease – most of them in hospital.

In the year 2000, the national confederation of parent-initiatives (Deutsche Kinderkrebsstiftung) funded a study to evaluate the actual situation of ambulatory palliative care for pediatric oncology patients in Germany (in a project called PATE). Questionnaires were sent out to all pediatric oncology departments asking them to state the present situation with the following results:

Out of 490 patients who died in 1999, 60% died in hospital and only 40% of the children at home, mainly due to the fact that only 10 departments had their own ambulatory care team or cooperated with an independent pediatric ambulatory care service.

The pediatric oncology department in Bonn is a medium size unit with 16 beds, 50 to 60 new admissions each year, a specialized outpatient clinic and a day clinic.

The local parent initiative has been active since 1983 and has supported many projects for patients and their families. In 1998 it started to finance a home care nurse, who should – equipped her with her own car – be able take care of all home visits, which until then were done by doctors and nurses at their spare time and personal risk – and of course, very unsatisfying for all. Soon it became obvious that one person alone would be not enough for a qualified response to all the demands. Thus, with the help and financial support of the German José Carreras Foundation, a team of 5 parttime nurses was established (with respect to their sponsor, the nurses call themselves ‘Las Carreras’), all of them experienced pediatric oncology nurses who used to work on the ward but prefer the part time employment due to their own family situations. Together they cover about 70 hours per week. The local parent initiative funds their cars, the necessary medical equipment, computers and mobile phones.

These nurses are closely supervised by the physician of the outpatient clinic who has the medical responsibility. They are – of course – not only engaged in palliative care, but offer home visits on demand.

Already in the first week in hospital, the family is introduced to the home care team and a first visit is arranged after one of the first regular discharges. At this point many questions which come up at home can be discussed and taken care of.

During the on-going treatment, the home care is continued only by personal request and/or if medically necessary, for example for teaching parents in the handling of a Hickman catheter.

In general, each patient is taken care of by his/her ‘personal’ nurse from the very beginning, which helps to build up a familiar relationship between the family and the nurse and eases the change into palliative care – if needed.

Many families do not need or want another home visit. But in those cases where the treatment fails and cure becomes less likely, home care is gradually increased.

All visits and contacts are documented in a data bank and can be evaluated.

Here are some facts specific to the palliative situation as collected from 1999 to 2002: until then, 18 patients were treated in palliative care (11 male and 7 female patients), of whom 11 had a relapses and 6 progressive disease. A third of the patients suffered from brain tumors, about one quarter had acute leukemia and three with Ewing sarcoma. Every patient and his/her families had the option to discontinue palliative home care at any time and could return to inpatient service. None of these families chose to return to the hospital.

The time from the last relapse or progress of the disease to the beginning of palliative care ranged between one month to two years.

The time of palliative home care lasted a median of seven weeks. The time of palliative care is generally shorter in malignant systemic diseases (like leukemia) than in solid tumors or brain tumors. Though these are known facts to the nurses, it is clearly avoided to give
any prognostic comments about the possible duration of this time. Instead, the nurses try to convey to the parents the importance of living every single day with their child and not falling into an attitude of "waiting for death". They can help to organize "events" such as visiting a concert or going out to the favorite restaurant.

Before the actual palliative care starts, an average of six visits per child has already taken place. These visits are demand-oriented, but often are necessary in regard to a possible future palliative situation. The nurses consider these visits as very important for setting up a comfortable relationship between them and the family as well as the patient.

The number of visits during the palliative care depends on the medical and the nursing situation as well as on the familial situation – on their self-confidence and ability to care for their child independently. The most common measures are pain control, decubitus prevention and nutritional support.

During the course of the project it was realized that many of the parents’ needs for support and counseling could be managed by telephone. Often a simple confirmation gives enough security to follow their own ideas and plans. An average of 25 phone calls, equaling six hours per patient was counted. This promoted the establishing of fixed hours for phone counseling, which allows parents and nurses to be prepared and in an undisturbed situation. It also allowed the team to reduce home visits without reduction of contentment. As an average they figured 31 hours per patient for home visits and 14 hours of travel time plus time for administrational work and team exchange (with the nurses in hospital, social workers, psychologists, physiotherapists, pharmacies etc.).

Tab.1

In the time here documented the nurses spent an average of 105 minutes per visit at home – the longest visits are in terminal situations. The travel time came to a median of 40 minutes and the distances for back and forth was approximately 30 kilometers.

In general, home visits are offered if the travel time does not exceed one hour one way. Otherwise the local general practitioner and a general ambulatory care service are involved and regularly contacted per telephone.

Tab.2: Time/visit spent on communication and nursing

The time for the visits was divided into the medical/nursing part and time for communication. The communication part comprises two thirds of the total visiting time.

Tab.3: Much more impressive are the qualitative results

In the years 1996 – 1998, twenty nine patients treated by the oncology department in Bonn died. Only one third of them died at home, though there has always been the offer to discharge the children in order to let them be at home for the last part of their lives. But before the home care service was established most parents did not dare to get themselves into a possibly difficult situation without the option of professional support. Since the ‘Carreras-Team’ started the home care for curative as well as for palliative situations, the number of children and parents opting for home care has nearly doubled.

The parent initiative gets very positive response from all families involved – specifically from patients in a palliative situation, for whom home care has made a remarkable difference in raising the quality of life until the end.

Meanwhile negotiations with the insurance companies haven taken place and we are optimistic that will be at least the medical and nursing parts of the home visits reimbursed as the insurances realize the clear financial benefit due to less hospital stays. But the indispensable part of ‘communication’ will still have to be supported by the parent initiative.

This talk presented at Meeting in Valencia, May 2004
Gerlind Bode
Board member of the parent initiative in Bonn (Germany)
Organising a Volunteer Programme
in the Paediatric Haematology Oncology Unit at the Johannesburg Hospital,
South Africa

Introduction

We have found that volunteers can play a vital part, and make a tremendous contribution, as members of the multi-disciplinary team within a paediatric cancer unit. However, it is not just a matter of taking in anyone who comes along, full of good intentions, and letting them loose on the families.

One needs to have a formal and rigorous process to make sure that the people who are accepted are suitable and appropriate, and that they are equipped with the knowledge and skill to make a positive contribution to individual children and families, and to the overall running of the units.

This paper gives some background to volunteers, and goes on to describe the process that we have found works very well at the Children's Haematology Oncology Clinic in the Johannesburg Hospital in South Africa.

About Volunteers

One definition of a volunteer is: “Any person, male or female, from a wide range – from young to older, from all ethnic, religious and racial groups, from a variety of lifestyles, economic, educational and social backgrounds, - working without monetary compensation for their service, in a cause or job they have voluntarily chosen”.

So the concept of volunteerism is therefore part-time paternalism / part-time active job, whereby work is executed with devotion, willingness and in support of the organisation. People give of their time and pool their resources, therefore enhancing the lives of individuals or others, and in doing so they enhance and enrich the community.

When one looks at why people volunteer there are many reasons. They may just want to give to others, or maybe have time on their hands, feel unfilled, or possibly have a skill they feel could make a difference to the child in hospital. The volunteer may also want to add a new dimension to their lives, or it may be the case of just wanting to meet others.

Volunteers are important and are always needed by parent support groups. People who give of their time can help out in many different ways – from running errands to maybe babysitting or taking a needy parent to the shops. At the end of the day, the parents and children in our care benefit, and at this level, there just needs to be some sensible screening of the people who come along to help.

However, there is also tremendous value to be obtained from volunteers who make a major commitment to work with the parents and children in the hospital environment. Professional staff, both medical and non-medical, also welcome volunteers, who help them overcome the shortage of staff and trained personnel.

BUT, training of that level of volunteer is absolutely essential, and we have found that a formal process for the recruitment, selection, training and ongoing management of the volunteer group is a necessity.

Need for a Formal Process:

So why have a formal process of selection and training? If for no other reason, it would be for the protection of the children and their families from undesirable people, or from people who just want to offload some of their own problems onto our already stressed parents. It is also important to protect our own organisation from any unfortunate consequences, and “unsociable” people.

But there are many more reasons apart from this, and it is important that the individual and the team have a set of common and agreed expectations from the partnership.

At the end of the day the volunteer must fit into the multi-disciplinary team, and they must be of a net positive value to the programme, as it is expensive to train and support the volunteers. It is of little value to invest time and effort in training someone who only stays with you for a few months, and then loses interest or realises that it isn't really what they want to be doing.

Over the years we have found, when looking for new volunteers, that we really must have clearly defined stages in the process of recruitment and selection, as well as a solid training programme with ongoing supervision. There also has to be a continuous development plan in place, and a code of discipline to be adhered to.

Recruitment and Selection

Recruitment can be done by way of media, when one would place an advertisement in the local newspaper or magazine, or by word of mouth, either by the existing staff or volunteers group.
It is important to identify what skills and qualities are required when recruiting a new volunteer force and, very importantly, where those skills are best needed – let that be in the hospital or clinic or at the Parent house.

Then having found people who are willing to give of their time, one must consider how soon should they start their role, and how much time must they give to the duty, on a daily, weekly or monthly basis.

During the selection process, it is critical to take note of the well-being of the volunteer, checking out their availability and commitment to the project, and making quite sure that remuneration is not expected. All volunteers must be prepared to attend the training programme, as well as the ongoing supervision.

Having identified potential candidates, it is important to put each and every volunteer through a formal interview before a panel. We have found that having 3 people on the panel creates the right balance. In our case these are: our social worker, the co-ordinator of volunteers, and our bereavement counsellor, who have all had many years of experience.

It is also important to check out any references that might be available.

**Training and ongoing management**

Our training programme, which has been found to work well, runs over 5 mornings, and has the following modules:

- Informational – about the organisation, who we are, what we do;
- Orientation – finding their way around the hospital and wards; or Parent house
- Medical Educational – about the illnesses that the children have;
- Skills and Counselling – development of listening and coping skills;
- Teamwork
- Conflict management
- Psychosocial - loss, death and dying.

Ongoing supervision of the volunteers is very important, and is done every 3 to 4 weeks. The volunteer must be encouraged to give feedback to their mentor and to be empowered to offload worries.

It is essential to organise "caregivers days" when outings are arranged which are team building; these are very popular and help to avoid burnout.

A continuous development schedule of lectures is also run, giving to the valuable volunteers: updates on medical information; life skills; bereavement counselling; coping skills; and updates on the organisation.

Amid all this there needs to be a strict code of practice – what the volunteer can do, and what they must not do! Confidentiality is paramount.

This is why at the end of the volunteer training programme we have a pledge signing ceremony and ask for the commitment of a minimum of one-year service period, and a minimum of a 4-hour shift per week.

**Qualities and factors for success;**

Some of the qualities that a volunteer must show are:

- patience and tolerance;
- being non-judgemental;
- being a good listener;
- to be able to befriend and make a difference to children and parents;
- and to build confidence and respect.

There are several Critical Success Factors in running a volunteer programme:

- The volunteer must feel that they are integrated into the multi-disciplinary team, and are able to give long-term continuity.
- Having enthusiastic leadership is important, as is having professional involvement and support.
- It goes without saying that the acknowledgement of the value of the volunteer in the multi-disciplinary team is critical, if you are to have a committed and caring group.

**Summing up**

Having a dedicated group of volunteers can make a tremendous difference to the running of a children’s cancer unit. They can help to lighten the load on the medical and nursing staff, and they can really make the visits to hospital for the children and their families seem far less onerous.

But it is important to make sure that the volunteers that are taken into this role have the right personal characteristics, and are able to cope with all of the emotional stresses that they will have to face on an ongoing basis. This means that they must have the appropriate initial training, and then ongoing supervision and support to ensure that they stay committed.

*This talk presented at ICCCPO-meeting in Barretstown, 2003*

Sadie Cutland  
CHOC Johannesburg, South Africa

**Acknowledgements**

The majority of the actual work in developing and running the volunteer programme at the Johannesburg Hospital is done by

Jill Graham (Volunteer Programme Co-ordinator);  
Alta Bence (Volunteer Programme Consultant and Social Worker); and Lynda Schutte (Bereavement Counsellor).

The author acknowledges that she has just done the write-up of this paper in an effort to share with a wider audience the dedicated great work that the team have done.
Regional Meetings
East European groups meet in Saint Petersburg

The first international meeting of representatives of Cancer Children Parents’ Organizations in Eastern Europe was organized in Saint-Petersburg (Russia) on Saturday, August 14th, 2004. The meeting took place under the patronage and financial sponsorship of the International Confederation of Cancer Children Parents’ Organizations – ICCCP0). The Non-Government Organization „Children and Parents Against Cancer“ (Saint-Petersburg) and its executive director Katerina Kiseleva invited participants to its office for this meeting. ICCCP0 was represented by Marianne C. Naafs-Wilstra (The Netherlands) and Gerlind Bode (Germany). The other participants came from different towns in Russia: Volgograd, Severodvinsk, Cheliabinsk, and Simferopol (Ukraine). Each of the guests talked about the experience of his/her own organization and the specific features of their work in their region. During the first part of the day, the discussion covered questions, connected with the work of the organizations with parents of children with cancer, with medical doctors and hospitals, where children are treated, with sponsors and representatives of the local or regional government. It was a heated discussion and active exchange of different opinions, especially on the topic of fundraising for parent organizations and active involvement of specialists – professionals as well as volunteers.

As a result of the discussion, participants made concrete plans for the nearest immediate future:
- exchange the results of the meeting,
- develop principles of joint collaboration,
- create an inter-regional project,
- develop and publish a joint electronic (Internet) newspaper or magazine,
- establish a joint website for all participants of the meeting (with information about all organizations participating in this meeting),

The idea of creating an inter-regional internet network was fully and enthusiastically supported by all participants of the meeting.

Our foreign colleagues were deeply impressed by the enormous work we are doing in Russia and the Ukraine. They admitted that at the time when parent organizations were started in Holland and Germany 20 years ago, the situation was very similar and that they came across the very same problems:
- lack of volunteers,
- the negative general public opinion that totally rejects all open discussion about cancer,
- absence of information about childhood cancer
- absence of mutual understanding between medical doctors and parents of cancer children,
- absence of contacts among organizations, representing one region (one country).

Parent organizations for children with cancer started in Russia and Ukraine only 6 – 7 years ago. But – as noticed by our foreign colleagues, they have achieved very positive results. This supports our idea of pooling our efforts in order to achieve much more in future.

In fact, the lively discussion started already on Friday, when our guests went sightseeing – accompanied by some group members, visiting the beautiful palaces of Petergoff and Pushkin city. On Friday evening, all participants were invited by the ICCCP0 representatives to a festive dinner during which many interesting stories about concrete everyday problems and the work in their organizations were told. Thus we could continue the discussion on Saturday with more depth on all relevant and important topics. We realized that on top of our common problems, there are some specific peculiarities characteristic for certain regions or towns. Participants of the meeting suggested several new ideas, that work better in some specific places than in others. The most important question was how to cooperate with officials, especially on a local level.

All participants supported the opinion that parent organizations for children with cancer must work as equal partners in their relationship with official government representatives of different levels. The future creation of a Russian Association of Parents’ Organizations would be really helpful in solving common problems with official representatives on the highest level.

Our foreign colleagues highly appreciated the meeting, pointing out that Russian and Ukrainian organizations helping children with cancer and their parents are presently are working on a highly qualified professional level.

Katarina Kisseleva
Children and Parents against Cancer,
Saint Petersburg, Russia
Childhood Cancer Parent Associations in Ex-Yugoslavia

Long-lasting materialistic deficiency necessarily leads to moral and spiritual poverty that we face day by day on all levels and within all social structures. The fact is that the poor are not by any means of less intellectual abilities and capabilities than the rich are, but due to the difficult conditions they are forced to think solely about their personal problems, coping with the everyday effort to provide for basic existential needs. This is just one of the reasons explaining a rather slow speed of reaching solutions in this region, as opposed to other areas where the system functions spotlessly, where basic existence is not endangered and people are in the position to think in broader terms.

In the past 10-15 years, humanitarian organizations in the territory of Ex-Yugoslavia emerged as a response to the destruction and were trying to make the best of the bad situation. However, these organizations did not appear as a result of a highly developed social conscience or the feeling that one needs to provide mutual help and support. It is very hard to have higher goals in such conditions so that the engagement of a couple of persons, materially as poor as many others but with preserved intact moral standards and a social conscience, could rightly be rated as heroic.

ICCCPO was founded just in these times, while war-like operations took place on the grounds of Ex-Yugoslavia and the country and people suffered under the burden of an unprecedented rate of inflation and the refugees were priorities (as they still are nowadays). In such circumstances the first Childhood Cancer Parent Association was established in Serbia.

The set of circumstances forced us to target our aims just on the pooling of medication and on the provision of related support; topics, such as thinking about forms of social support, education, information, reconvalescent treatment of cured children and their families, as well as the provision of the care and support for the families who had lost their children were neglected due to the general situation and existing prevailing circumstances. Money was collected both for the necessary medication and for the burials and transport of the deceased to the families that did not have money for this.

Unfortunately, although the war is finished, unpleasant consequences of long-lasting character still exist and they are such, that people in general have developed a “not interested” attitude in reaction to words like “help” and “humanity”.

For that very reason, it is hard to place the issue of childhood cancer at the top of the current events. Despite the fact that money is the major precondition to enabling maximal treatment possibilities, I believe that there are still things even more important: such as information and the education of both patients and their parents, as well as of the whole public area!

It is easier said than done, since we face obstacles which are hard to overcome:

■ Just a few children know the truth about their disease.
■ Parents are ashamed and afraid of the disease.
■ Many physicians (not all) place themselves in the role of Gods, thus not inclining towards the idea to have parents involved in the treatment although they are, due to the participation and attendance of many congresses, acquainted with the significance of the role and the importance of the Parents’ Organization.
■ There is a prevailing attitude that places the Parents’ Organization in the role of a service intended to serve the needs of the hospital and its medical staff.
■ Despite their poor economic resources, parents tend to give money to doctors and other medical staff, thus creating a kind of “warranty” that their child is to be offered better treatment and care: unfortunately, it has become very widespread, almost an unavoidable practice.

This is just a part of the host of problems we face every day, problems which are not necessarily connected to the matter of money.

Frequent media appearances attracted the attention of the public, parents and patients. An important precondition to be fulfilled prior to media appearance is a certain standard of education. However, a bigger problem is that parents and their families are not ready to talk openly, in public, about their personal problems.

This needs a certain degree of valiance and courage since it is really hard to talk in public about one’s greatest pain. However, it proved to be very efficient to demonstrate to the public that this does not happen just to “the others”; quite the contrary, childhood cancer is a widespread disease. Following the NATO Alliance
bombed in 1999, an increased number of sick children has been registered on the territory of Serbia, Kosovo and Montenegro. The bombs contained uranium. This is one of the issues we should engage in and present the truth and the facts to the public.

One of the noteworthy projects of ICCPO is the organization of regional groups. Rating myself as fairly well-informed about the existing conditions in my country, I believe it is possible to form such an organization on our own grounds. The fact is that the first step is the hardest one, even much harder than I first thought. My attitude was that after the experience we passed through with our children with cancer, we have nothing to be afraid of, since the most severe possible circumstance for a parent is to have a child with a life-threatening disease so that this fear surpasses all the other fears.

From that point of view, I addressed parents’ organizations from Ex-Yugoslav countries with an open heart, inviting them to establish communication so that we could overcome the numerous common problems we presently face.

Apart from the association “A Heart for Children with Cancer” in Bosnia and Herzegovina - Sarajevo, I received a rather cold reply from every organization, accompanied by the explanation that it was too early for a step of that kind. In spite of my persistence and sincere wish to cooperate, I came to the conclusion that I am rather isolated in my hopes and attempts and that there are only a few people that have a social conscience and dare to go further, to bury the battle axes and turn toward progress, to offer their hands, thus doing their best to enable and provide the right to live for children with cancer. Sadly to say, the germs of hatred were spread and mistrust still triumphs over love, sincerity and faith.

It is hard to overcome this, yet not impossible. Slowly it is happening, not as fast as we would like it to, but step by step, probably in a year, or two, or three... but I am strongly convinced people will re-unite and gather just as we in ICCPO did, coming from different countries, various cultures, languages, economic conditions; all of us gathered with the same problems, aims and wishes defined in an effort to enable maximal treatment possibilities that are likely to have the highest cure rate for children with cancer.

Irina Ban
President of the National Association of Childhood Cancer Parent Organizations of Serbia and Montenegro
Member of the “ZVONČICA” - Mother and Child Health Care Institute, Belgrade, Serbia and Montenegro
ICCCPO Executive Committee Deputy Member

We are the winners

As our years in the oncology department at Advanced Paediatric Centre of Postgraduate Institute of Medical Education and Research go by, we have understood and known that strength and positive outlook is in abundance in the children. These little ones show amazing courage and resilience; they indeed are examples for all around them. We as caregivers, parents, and volunteers are enthused with some of their spirit too. This year saw a lot of major developments and we along with the parents and doctors felt that our work with the cancer-afflicted children progressed well on almost all fronts. This year we were able to sponsor the treatment of more children, we were able to reach out to more families and were able to make a difference at large.

This year at the ICCPO meeting at Barretstown, Ireland, Sahayta was awarded full membership and we are proud to say that Sahayta is being recognized for its work internationally. The ICCPO meeting was attended by Dolly Soni and me and it gave us an insight into the approach adopted by the international organizations. We are trying our best to adapt the feedbacks according to our country’s needs so that we can provide adequate support to families fighting cancer.

As the joint celebration of International Childhood Cancer Day and Cancer Survivors’ Day was approaching, we decided to put up a fancy dress show. Since many children were from far off places, we started earmarking the participants almost two months before the function. In spite of the numerous odds against them, the children were greatly interested in presenting the show. Each one came out with his or her novel...
idea and helped us to choose a dress of his or her own choice. In some cases, their imaginations ran so wild that we went berserk searching for the suitable attire.

Our efforts were well rewarded when children and their parents came forward for the celebration of childhood cancer day. The age groups were varied, ranging from 1½ years to 19 years and so were the backgrounds. They came from different parts of the country, spoke different languages, their perceptions were different but they shared the common platform where medicines and syringes, hospitals and doctors had become an integral part of their lives. Together they stood, united by their disease, in grit and determination to prove that they were the best. Though some children were on intensive treatment, they practiced the whole morning and staged the show in the evening.

Tiny tots dressed as animals, the youngest child Ripu, 1½ years of age, was seen romping as a butterfly. There were others too, Purva (6 years) as a rabbit, Rajan (3 years) as a mouse, Kamalpreet (5 years) as a bear, Daksh (3 years) as a bird. They danced to the tunes of “chun-chun karti aayi chiriya”.

I would especially like to mention Rajan a 2½ year old boy who was dressed up as a mouse and recited a poem too. It seems that though this is Rajan’s first visit to Chandigarh, to PGI, it is not the same for the family. They have been to Chandigarh before, fifteen years ago when Rajan’s elder brother was diagnosed with ALL. For the family, the nightmare is being repeated. Rajan’s elder brother was lost to ALL and the family’s worst fears had been confirmed. Rajan too has been diagnosed of suffering from ALL. He requires intensive chemotherapy and prolonged hospitalization. The family is once again facing similar trauma, similar uncertainties and at the same time hoping that with improved methods of treatment and care, they will indeed win the battle. We at Sahayta as volunteers and caregivers, hope and pray that the family emerges victorious the second time.

After the monkeys and bears came, Simran and Kavya dressed as fairies and Kush as Santa Claus. They indeed stole the hearts of the audience. Sapna, Monica and Sarita made breathtakingly beautiful brides. They wore mehandi on their hands and were dressed in their bridal finery.

A special tribute goes to Monica Sudan, a 12-years old leukemia survivor who had relapsed and was terminal at that time but made a pretty bride in pink lehnga-choli with dupatta (a long skirt, blouse and a long scarf). We lost her at the end of April but she will always remain in our hearts. Strange are the ways of God but I guess we cannot even question him! A life lost too soon – as mortals we finally have to accept what comes our way but definitely not before putting up a fierce fight. Maybe she was a favourite with God.

Young boys dressed as Bhagat Singh (Shivam, 13 years), Army Officer (Pawan, 14 years) and Police Official (Vinod, 12 years) marched to the tune of “nanna muna rahi hun”. The show culminated with the grand finale where each participant introduced him-or herself. And of course, last but not the least, we had Dr. Amita Trehan, Addl. Professor (Paediatric Oncology) as a Penguin (Pingu from cartoon network). She had merged so well with the children that almost no one knew till we asked her to address the audience. Three cheers for the supportive doc!

Sahayta volunteers were involved with the children at different stages of preparation. Mrs. N. Tuli and Mrs. S. Bhan for active support and guidance. Mrs. Sharda Ahuja, Mrs. Raj Gupta, Mrs. Dolly Soni and Mrs. Mithilesh Indramohan worked whole-heartedly to bring out the best in each child. We all as a team choreographed and presented the show.

Aaradhna Mittal
In charge of Sahayta bal Sahyog

Children celebrate the International Childhood Cancer Day (ICCD) with a fancy-dress-party.
Schooling Integration Program
of the Spanish Federation of Children with Cancer
(talk presented at ICCPPO-conference in Oslo)

I would like to present the schooling program organized by our Spanish federation since September 2002. It is financed by a private initiative. This program intends to solve, to some degree, the schooling needs of Spanish children with cancer, whose regions do not attend to these needs adequately. And it will run until the attention is properly covered by the public institutions. In this presentation I would like to explain not so much the program in itself, but the different steps we took to develop the program.

There are members of our Federation in most regions of Spain except the western regions and the Canary Islands. We are trying hard to establish them in every region. But sometimes it is very difficult because there are no specialized centers, or because the region is very big and the children live far away from each other.

The different regions of Spain have a high degree of autonomy to decide how to attend to the needs of the population in health related matters, education and social welfare, especially for small groups of the population like children with cancer. That is why one of the federation’s main priorities is that all children with cancer in Spain should have the same opportunity for survival and the best quality of life - independent of their place of residence.

This schooling program was developed due to the fact that many regions were not meeting the schooling needs of the children. In areas with no parents’ association, the federation runs the program directly. Where there are parents’ associations, it is a combination of resources between both organizations.

Aims and development of the program
Firstly we needed to demonstrate to public institutions the needs of the children diagnosed with cancer, so we conducted a pilot study.

Once we recognized the needs and factors involved, we developed the standards of a schooling program to cover the needs from diagnosis till full return to school.

We investigated what really happened with the school attention of these children in the different Spanish regions.

We developed a schooling integration program at national level to cover some needs that nobody was attending. It’s impossible to cover all the needs as it would be very expensive.

I. Pilot Study
The objectives of the pilot study were:
- to collect data about the child’s school activity from diagnosis until his full return to school
- to compare his school achievement prior to diagnosis and months after his full return to school
- to find influencing factors and make conclusions
- to develop standards for a schooling program for children with cancer.

Characteristics of the pilot study:

| subjects: | 29 children (6 died before end of study, so data refers to 23) |
| sex: | 10 boys / 13 girls |
| ages: | 10 children between 7 to 11 years old (primary school) |
| | 12 children between 12 to 15 years old (obligatory secondary) |
| | 1 youngster 16 years old (high secondary) |
| period: | 2 school years (from September 1996 to June 1998) |
| data collection: | interviews with family, school, hospital school and home teacher, if there was any. |

Two comparison tables:

<table>
<thead>
<tr>
<th>Period not attending school/achievement</th>
<th>number of children</th>
<th>moment of return to school</th>
<th>achievement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>continued attending school</td>
<td>good</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>returned in May 97</td>
<td>good</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>returned September 97</td>
<td>good (9) bad (8)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>returned February 98</td>
<td>bad</td>
<td></td>
</tr>
</tbody>
</table>

In the first table the factor we studied was the period not attending school. In those years children were hospitalised for longer periods and we can see that there were a high percentage of them not attending for at least the whole school year. No attendance is a risk factor for poor achievement but not the only and maybe not the most important.

School activity during treatment/achievement prediagnosis

<table>
<thead>
<tr>
<th>school activity</th>
<th>good achievement prior to diagnosis</th>
<th>bad achievement prior to diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>teachers at hospital and at home coordinated with school</td>
<td>continues with good achievement</td>
<td>same achievement or better</td>
</tr>
<tr>
<td>no teachers and/or not coordinated</td>
<td>bad achievement</td>
<td>worse achievement</td>
</tr>
</tbody>
</table>
In the second table we studied two very important factors:

- school activity of the child during treatment
- pre diagnosis achievement

We can see that if the child continues his school activity and this activity is programmed by his school of origin well-coordinated with the hospital and home teachers, his achievement will remain as good as prior to diagnosis or even better.

However, if school activity is rare or not well coordinated with what is done at the hospital and at home or has no relationship with the school of origin the achievement worsens both for good and not so good students.

Conclusions about intervening factors

Family motivation towards school activity during treatment: the family needs to realise that, even though the child has a serious illness, his life needs to continue as normal as possible.

Child's attitude and achievement prior to diagnosis: some children (especially older ones) are not very keen on school activity and sometimes the illness can be an excuse to quit anything related to school. If this attitude combines with poor motivation by the family, the risk of failure is very high.

Written information for schools about the illness and schooling needs of the child is very important / essential.

Atmosphere at hospital school: it is not a therapeutic game but it is not a normal school. Maybe the achievement is not so important as to keep school habits and the relationship to these activities, to prepare work when the child is at home.

Coordination between school/hospital school/home teacher. It is essential that the child sees the work as a continuity supervised by his home school and that his work has a meaning.

Home teacher not a volunteer. It gives a formal aspect to the work. We are not entertaining the child. We are helping him to cover his school program.

Mostly it is easier for children to work harder at home than in hospital.

Undesirable variable: we are sure that many of the results of this pilot study were influenced by the interviews we were holding. Our interviewing the families and the teachers changed attitudes and promoted coordination which influenced better results.

II. Standards for a schooling program

Four important agents that need to be well coordinated:

1. Hospital school (brings a normal element to a strange/hard situation)
   - motivates child and family in a moment of shock and uncertainty
   - contacts with school always with permission of the family and gives written information directly or through the family.
   - needs creative/flexible atmosphere to stimulate

2. School of origin (It is the real thing; hospital school/home teachers are exceptional elements while the child cannot attend school.)
   - needs written information: They need to know about the illness, the treatment, how to treat the child, how to inform the classroom, etc.
   - coordinates/programs activities: It is essential that the students school which knows his school level develops a realistic program that the child will be able to accomplish in his actual treatment situation.
   - promotes relationship with peers
   - prepares child’s return to school

3. Home teacher
   - needed until return to school
   - activities coordinated with school and hospital
   - not volunteer

4. Family
   - motivates child towards school activity
   - keeps close contact with school
   - helps to create an atmosphere for home teacher

III. Comparative study on how the different Spanish regions are covering schooling needs of children with cancer

We analysed three elements: written material, hospital school and home teachers:

Written material for information of the schools.
- Different booklets had been edited through the years by parents’ associations of different regions. Some had outdated information.
- It was decided to have a national guide for schools with revised information of new treatments and needs.

Hospital school
- almost every children’s hospital in Spain has a school
but there were great differences among them with regard to activities, number of teachers, attention given when child was isolated
coordination between hospital school/school of origin was practically zero in most cases.

Home teacher
- Only two Spanish regions had by law home teachers where the child was studying the obligatory curriculum
- The rest covered some cases through volunteers of parents' associations or other NGOs. In some occasions local public institutions provided the service out of goodwill.

Program of the Spanish federation at national level for schooling needs not yet covered by public authorities.
To give a minimum coverage according to the standards indicated we pointed out three major necessities:
- information guide for schools
- home teachers
- coordination between teachers involved

Information guide for schools
- It is a very complete guide, with a chapter dedicated to the illness and treatment
- another chapter about how cancer affects the child depending on his age.
- then there is a chapter about the parents, another for siblings
- one special chapter for the terminal phase
- and at the end a vocabulary with the most frequently used terms.

Home teachers and coordination
Another problem was the need to have home teachers and to coordinate the work the child did at hospital and at home with the guidance of his school of origin.
This service is running since September 2002
The number of children attending throughout Spain:
school year 02-03 .................. 23
school year 03-04 .................. 32

Development of the program
The first thing we did was to hire a national coordinator with the following tasks:
- Those regions without the public service of home teachers can demand this service to the coordinator of the program. Demands come from parents' associations, school hospital or directly from the family.
- The coordinator contacts the family and the school of origin directly, sends the information guide and finds a way to cover home tuition (first demanding the service to the public authorities, and if this doesn't work, paying the teacher directly).
- The coordinator does a follow up of each case until the child returns to school.

Looking to the Future
The Spanish Federation program is designed to cover gaps in services provided by local authorities to cover schooling needs of children with cancer. We look for a future where all schooling needs of children with cancer are covered by law according to the right of every child not to interrupt their tuition due to his illness.

When existing, actual regional laws only cover schooling needs of sick children during obligatory tuition (6 to 15 years old). We look for a future where the law covers the needs of children from 3 to 5 years old and adolescents from 16 to 18 years old.

Some children will still need special help after returning to school. We look for a future where children will be helped to keep the same level as their peers.

Some children will have long term effects which will hinder their intellectual performance. We look for a future where children have a close follow-up after the treatment so that these problems are detected and rehabilitated (if possible) as soon as they appear.

Hortensia Dias Asper
Spanish Federation of Children with Cancer
www.aspanion.es

Help for children with cancer in Belarus
I have been planning to write to you for a long time now. But because our life – I mean that of our non-profit organization – is very complicated and sometimes unpredictable, the letters were put off. I always remember you, though, when I receive the latest brochure about the works of ICCPO. Thank you for sending it to us regularly. I find the organization's work very interesting.

I am thankful that we are not forgotten, although we never joined ICCPO officially and could not take part in the conferences. The reason is lack of financial resources. When I say our life is complicated, I want to say that the government is more and more taking control over our work. Still we continue, because the number of children taken care of by the organization “Children in Need” is steadily rising and the problems connected with their treatment and rehabilitation do not become less.

I will try to give you a picture of what we have been doing recently, of our success, and I want to ask you to publish our information, to make sure that other organizations know about our association. This way we would feel to be part of ICCPO.
The “Belarussian Organization of Children in Need” is a non-profit organization and was founded in December 1990 by parents of children with cancer. In 18 cities of the republic subsidiaries of the organization were founded. Unfortunately, the number of children with cancer is growing. In 2001, 175 families became members of our organization. In 2002, 245 joined and in 2003: 243. More than half of the ill children are younger than 7 years.

The main goal of the organization is to support families of children with cancer and special clinics for these children, with the aim to ensure a high quality treatment and rehabilitation. This is why the main activities of our organization are collecting financial means, medication and medical equipment from foreign partners of the pediatric clinics of the republic.

Through the organization’s initiative and the financial involvement of our foreign partners the following projects were realized:

1992, a sanatorium with a kindergarten and elementary school for children with cancer was built in Minsk. The classes are organized up to 3rd grade.

On the site of the republican children sanatorium “Ostroschizkij Gorodok” in January 1998 a rehabilitation ward for teenagers with cancer was opened. The ward has the necessary equipment and highly qualified staff.

With the help of our foreign partners, specific medication and equipment worth $120,000 was given to the Republican Pediatric Oncology/Hematology Center and the onko-hematological ward of the Mogilew Clinic. Because the Children’s Center for Oncology and Haematology constantly has problems with the financing of the medication, this kind of help is of great importance. This way, the newest medication can be provided, which is not bought by the ministry of health. For some children, this expensive medication is the only chance to a positive treatment result. We are happy to be able to help.

Vitally important for the Pediatric Oncology/Hematology Center as well as the parents is the hostel for parents of cancer sick children that come from different areas of the republic for treatment at the day-clinic, for control, etc. The Pediatric Oncology/Hematology Center does not have the possibility to provide rooms for parents and children, because it is constantly overbooked. The rooms in the hospital can only accommodate two ill children at a time, right now there are four, sometimes five children who would need a bed. In case they don’t get a room in the hostel, staying in a hotel would be the only alternative for the parents, although most of them cannot afford that for a longer time. However, the organization cannot fulfill all wishes of accommodation by parents and children in the clinic.

Together with the Health Ministry and the Pediatric Oncology/Hematology Center we plan to build a “Mother and Child House” on the site of the hospital. Our foreign partners are willing to participate financially in the project and collected 80,000 $ for this purpose. We are still searching for more partners who want to take part in the realization of the project.

The festival “Smile” for children who are finished with their treatment takes place every year. About 50 children with their parents and siblings join (in total more than 1000 people) to celebrate. We provide games, children groups give performances and everybody receives a gift. Our partners also come to this festival. Of course, we do not forget the children being treated in the Children’s Center. For them, we have events with gifts, too. We support children financially who are in the clinic without parents, so the children receive good nutrition and fresh fruit.

Our main problem is the constant financial distress, caused by ongoing costs (rent, telephone, electricity, water). Unfortunately the government does not give tax reductions for non-profit organizations and we get almost no money from banks, commercial companies, etc. It is disadvantageous for them to give humanitarian help, because there is a rather high tax on donations. This is why you can say that humanitarian deeds are not “in” in our country. We can afford our work only thanks to our foreign partners and friends.
Regional Group Reports

2003, we were asked to return part of the premises, where parents with ill children were accommodated to the landlord.

In spite of all the difficulties we constantly face, we want to continue our work, because parents come to our organization with their problems every day. We give psychological, legal and other advice. Every year, about 1100 children that were treated are invited for rehabilitation by our partners. Most of the parents are thankful for the help and support.

We hope that there will soon be a law for the regulation of humanitarian help, which was put off a few years ago. Hopefully the needs of non-profit organization will be recognized.

Evegenij Ukrainzew
Chairman of the organization "Children in Need"

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The Heart and Soul of Movement
The practice of adapted physical activities (APA) in collaboration with pediatric cancer institutes

The Concept
My idea germinated between 1991-1993. In those two years of my life I was introduced to children suffering from cancer. My brother was diagnosed and hospitalized on the Cancer Ward in Nancy, France and later Besancon. At a time of life when emotions were overwhelming, sadness and feelings of joy collided. The joy came in a sense of “Spinoza” (our senses intoxicated by emotions a devotion to triumphs and downfall, our feelings overpowered by emotions of our being).

Observing the situation I impulsively started to ask the sick children questions and listened:

I HEARD what the children wanted, the desire to be like everyone else, to live every day to the fullest, to endure and conquer, fight to the end.

I OBSERVED their reactions, when they conquered simple things like walking or playing, riding a bicycle, being with friends and family, or simply tapping a balloon to keep it airborne. Ordinary tasks that we take for granted every day. Cancer was robbing the children of this, a poignant testimony written by Emilie in her diary.

I wanted to keep the children’s hope “airborne” and could finally listen to the children’s propositions, even though the children’s limitations and expectations were obvious due to the disease.

A solution came when listening to a third year sports teacher student of APA, (those who study the mobility of handicapped or ill people). I decided to respond to these ideas with a profound devotion and gave my heart and soul to help sick children: these children should and would continue to exercise their bodies, even with their limitations, the techniques offered by the APA. The Head of the Department of Cancer, Professor Dr. Sommelet, her heart and soul devoted to her program, opened the door for a pilot program to adapt their procedures, to accommodate ours. This allowed the inconceivable and incompatible to be adapted, to overcome the potentially dangerous pathological hurdles. The impossible became possible.

Now my whole heart was in this project, the adoration for my cancer stricken brother fuelling the fire, he passed away, but the project lives on today.

Participation
Confronted by inconceivable hurdles in cancer, it is possible to re-invent other aspects to accommodate different situations. I psychoanalyzed the situation, my adoration for my brother, could I orientate my sentiments without prejudice or would my emotions dominate the situation.

In the beginning I was confronted by my own limitations: would I be able to represent, be supportive, initiate to deal with the ideas of the APA and the aspects of children’s cancer? Without mediators to help me to apply the same expertise of the APA, when situations concerning the children who are suffering. The children who are fighting to live and for the children whose battles are far too great. We support family and friends to cope with the hardest part of all, death.

We cannot erase the events from our experiences with everyday life, for the children we can apply our strengths and weaknesses to support their lives, without therapeutic, formal techniques, style and being
critical. We can help them accept their body limitations, as they are real. We can build their self-esteem, working with our supportive teams, our physiotherapists and all those involved rebuilding the whole body and soul.

Our goal is to reintroduce a style of basic team effort done with affection. APA introduced me to this method, allowing me to work and achieve these goals. APA placed me with research students working to achieve methods of comprehension, concepts, and situations where every aspect was psychoanalyzed. They taught me to distance my emotions from the situations, sometimes very difficult situations. The students and I worked together as a team helping each other to achieve, and support and perfect to help those who needed us the most. The practical goal of the APA system teaches proper methods of physical training, emotional and creative approaches to difficult situations. The APA concept originated in Quebec, teaching in social training to help the population of handicapped in all categories.

The Application
The educational aspects are simple and the object is:
- satisfy the children according to individual age, family history, past sports abilities
- satisfy the parent's specific concepts and ideas, how their child should be handled in every aspect of educational and emotional support
- to correspond with medical developments, changes in therapies and integrating diverse social events, like concerts, parties, and animated shows
- to give a higher quality of hospitalization stays for each child.

The practice of the APA is to have a space or room where each individual can express his/her emotions, to listen, ask questions be aggressive, laugh, cry or just be, without judgments. Like a comfort room, where all emotions respected, an empowering place. This system works, proven by the APA, testimonials from people whose lives were changed and helped by these acts of love, the heart of the movement.

The Effects
- Ten years of experience, 1600 reported cases, clinical research studies, we can conclude that the APA
- permits us to live like before,
- changed the concept of integrated sports for physically handicapped, adapting individual talents to achieve goals
- helped to modify hospital conditions and create a better atmosphere for all concerned,
- its specific goal is to develop individual skills for the physical and mentally handicapped.

The Perspective: Opening the Door to Others
Response to the large demand for our services. Listening, learning and practicing what we are teaching.

Continue the vital training of students and faculty in sports education (27 students 3rd and 4th year associated with the APA). A practical plan, placing students in hospitals around Europe, now educating students in Strasbourg, Grenoble, Bordeaux and today the frontier of Lausanne. The goal is to keep the interest in this subject alive, hoping to inspire others to choose and enter into this curriculum.

To associate the APA system to other services, pediatrics, cardiology, trauma centers. The possibility to introduce the system in centers treating anorexia, bulimia, obesity and substance and physical abuse centers.

The research:
This project of the Foundation of France opened the door for a cultural movement. Christine Pepin, responsible for an affiliation of the APA curriculum in the sports department of Nancy, has been able to orient the heart of the organization into contemporary dance. Contemporary dance enabled us to put away our inhibitions, liberating body movements. Transforming gestures and body movements to show us another view, opening our imaginations to choreographed music we see suffering, sensuality and pleasure. This emotional project exhibited in the entrance, enables us to visualize how cancer robs the children bodies of strength and movements, and gives the children a chance to show this through dancing.

Working together in research with the French-Swiss, evaluating the effects of the practice of the APA on children suffering with cancer, and associations for pediatric psychology with the Liaison of Lausanne. Distribution of these experiences through medical publications.

The Support with years of experience:
The APSEM was established in 1997 by the parents of sick children who were treated for cancer. We come together speaking about our past and speaking freely how we felt being confronted with cancer. The same subject repeats itself over and over and we offer more activities for the children who are hospitalized. The APA practices are offered 5 times a week with a great choice of activities, sports games where medals are received for participation, Emile Yung, chef of the Restaurant Crocodile in Strasbourg made special food for the participating children. After the children's stay in hospital they can participate in the Roland Garros Day (mini motorcycles, side cars, dance shows, etc). I thank each and everyone of these wonderful people who donated time and money and the hospital personnel for their great assistance. Without all these fantastic people my ideas would only be dreams, today it is a reality.

Association pour la promotion du Sport chez l'Enfant Malade
9b, Avenue Foch, F-57 000 Metz
The LOSEV-Festival

Every year in Turkey, approximately 1200–1500 new patients who are in the range from 0 to 16 years are newly diagnosed with leukaemia. The treatment takes three years and the cure rate is about 90% for the standard risk group. Apart from the social and psychological support – which are also crucial to overcome the disease – approximately $100,000 are needed for the medical treatment of each patient.

LOSEV – Foundation for Children with Leukaemia – is a non-profit organization, which offers a wide range of services without any governmental support. LOSEV is totally supported by donations from generous and helpful people and companies. LOSEV provides information, financial assistance, emotional support, medical diagnosis and treatment support to almost 1,500 children affected by leukaemia and their families, who have no social security or are too poor to afford any medical treatment, totally free-of-charge. At our hospital, LOSANTE which is established just for the children with leukaemia, we have maintained good nourishment conditions and a sterile environment required for the treatment of leukaemia and provide service totally free of charge. Since 87% of the registered families to LOSEV have a monthly income of less than 200 USD, LOSEV also gives social assistance to the families who experience financial hardship.

We support education and give scholarships to almost 360 children. We provide families with necessary goods, such as: coal, clothing, food, cleaning supplies, toys, furniture and school supplies.

Our foundation also carries out projects and campaigns to provide better health and social-economic conditions for our children and their families and to increase public awareness about the issue. For this purpose we started a campaign called "Goods Distribution Festival". With this campaign we aim to distribute various materials costing almost 550 Euros to one thousand families with children who suffer from leukaemia. This campaign is carried out at all cities of Turkey between August, 25th and – October, 15th 2004 and ends with the big Final Festival Day, held in Ankara at October, 17th.

LOSEV and our families were in Istanbul for the Festival Day. The materials given to families, were within a wide range from clothes, furniture, food, stationery goods, toys to white goods etc. With the support of our volunteer members and the donations made by generous and helpful people and companies, it became an unforgettable day for our children and families. The festival went on all day at the distribution site. We set up many booths for each good. The families bought the goods according to their needs with the free coupon checks given to them by LOSEV. With this system, not like the other distribution campaigns, the families were not given goods which the companies considered that they may need, but rather the families chose the goods themselves according to their own decisions and needs. 200 families benefited from this organization by the support of helpful people and private corporations. The Festival itself became a great opportunity to encourage families in their struggle against leukaemia and also to encourage volunteers and sponsor corporations in terms of social responsibility.

We also realised one of our initial aims, which is to increase public awareness on the issue, by promoting the festival via mass media.

With such organizations, LOSEV aims to provide the highest possible quality in the life of each child with leukaemia and his/her family. Anyone can support LOSEV to reach this aim by supporting us both financially and spiritually, by being sponsor of our campaigns, by assisting us in introducing and performing our projects, by making donations in kind such as clothing items, computers, bicycles etc.

We as LOSEV believe that by sharing ideas, experiences and information, we can improve the life of our children and provide them with a healthy and therefore better future. Having this in mind we would like to share our experiences with others who are battling leukaemia all around the world.
Presentation of a newly elected ICCCPO-member

UNAPECLE

(Union nationale des associations de parents d’enfants atteints de cancer ou de leucémie) is a French national parents’ confederation, established in June 2003 and consisting of different regional organizations whose main objectives are:

- Unite, federate and promote French Childhood Cancer Parent Organisations in order to coordinate their common actions
- Share the know-how of those organisations
- Be one unique voice towards the French government for the health conditions and human services
- Create and favour better communication on scientific, medical matters and inform about childhood cancer

We count 19 organisations and among them 12 are in the committee and five in the executive committee administrated by our Chairman Philippe UNWIN.

UNAPECLE has different working groups:
- School integration
- Paediatric Medicine

Relation with the Health ministry:
- We are contributing to the National Cancer Plan created by J. Chirac in 2003
- Know-how and experiences exchange
- International relationship with ICCCPO
- We meet every quarter in different towns of France where the federate members are located.

UNAPECLE is now one year old. We are very happy to exchange with you and hope that we shall bring you our French experiences and take great lessons from yours.

Monday, 13 September 2004
Cécile Galzy
UNAPECLE
354 Route de Ganges
34000 Montpellier, France

The Chemo-Kasper booklet is available in many languages.
Visit our website to find your language.

www.icccpo.org
Claudia L. Chamorro

A Time to Live
A Message of Love and Hope in a Fight for Life

Published in Spanish by Editorial Hispamer
Managua (Nicaragua), January, 2003

Tolentino was a Nicaraguan child who, upon being diagnosed with leukemia when he was ten years old in September of 1991, traveled with his family to the United States in search of medical treatment — a treatment that ultimately required a matching bone-marrow transplant. A transplant donor could not be found owing to the lack of a wide-ranging register of potential donors, and Tolentino died in the U.S. in April of 1996.

Tolentino’s greatest concern upon finding out that he would die as a result of his illness, was his realization that he wouldn’t have the opportunity to study, to go to college, to develop professionally and thus be able to contribute to society. His greatest anguish was that he would leave his mother behind in the deepest sorrow, and that he didn’t know anyone in heaven. His aspirations, the dialogues about death that he had with his mother, their intent to find sense in the irrational, and other details about the dramatic experience of this child are recorded in A Time to Live.

So far, this text is only available in Spanish. The author (Tolentino’s mother) would be interested in contacts that could help her to translate and publish this book in other languages.

Dr. Fred Epstein and Joshua Horwitz

If I Get to Five:
What Children Can Teach Us About Courage and Character

(available through Henry Holt and Company
115 West 18th St., New York, NY 10011
www.henryholt.com)

Dr. Epstein and writer Joshua Horwitz relate the unforgettable experience Dr. Epstein has shared with children and the lessons he has learned from them. Stunningly, Epstein meditates on these lessons at a time when they parallel his own struggles. Some time ago Epstein suffered a near-fatal head injury while bicycling that left him in a coma for twenty-six days. As he gradually returns to life during a year of painstaking rehabilitation, he shares with the readers the journeys of his young patients and his own remarkable saga.

A new computer game that battles cancer cells

The object of the game is to destroy all mutated cells and to collect the seven shields that provide protection from common side effects of chemotherapy. The shields are guarded by “monsters.” The game can be downloaded from: www.makewish.org/ben

I am writing to ask for your help

I am a licensed clinical social worker as well as a bereaved parent. My daughter was 8 years old when my son died very suddenly. He was 11. I am now doing my Ph.D research on sibling death and parental support and I am hoping that you can help by alerting people to the study. I am looking for adults of at least 18 years of age who were between 8 and 13 when their sibling died from any cause, at any age. If you know of anyone who fits the above criteria, I would appreciate your alerting them to the research study. The questionnaires can be accessed over the web at www.sibbrief.com. Those without internet access can write to me at:

Susan Rabinaw, LCSW, 183B Nassau Street, Princeton, NJ 08542, or fax me at 609-921-1007 and I will mail the questionnaires to them with postage paid return envelope.

Thank you for your help.

Note:
Please inform the secretariat if there is any change in your address
C/o VOKK Schoustede 2d
3431 JB Nieuwegein, The Netherlands
email: icccpo@vokk.nl
**Announcements**

**February 15, 2005**

International Childhood Cancer Day (ICCD)

for more information see: [www.ICCCPO.org](http://www.ICCCPO.org) or contact: Geoff Thaxter (s. p. 28)

**September 21-24, 2005**

SIOP 2005

Will be held in Vancouver, Canada

Preceded by an ICCPO parents program and a survivors meeting as well as a day of educational workshops on specific topics look for more information on the ICCPO website ([www.icccpo.org](http://www.icccpo.org)) or on the SIOP website: [www.siop.nl/siop2005](http://www.siop.nl/siop2005)

**Special announcement for the ICCD 2005**

Through My Eyes:
A Day in the Life of Children with Cancer Around the World

Have you ever wondered what the treatment of childhood cancer looks like from a child’s perspective? Doctors and nurses can treat their disease and carefully follow their progress. As parents we hold their hands, wipe their fevered foreheads and calm their fears while they walk this journey. But do we really know what they see or what they feel? We wondered and maybe you might have wondered too. Perhaps we think about their experiences because we are all intimately involved with their treatment and care either as health professionals, parents, siblings, or loved ones.

The International Confederation of Childhood Cancer Parent Organizations (ICCCPO), the International Society of Paediatric Oncologists (SIOP) and the SIOP Nurses Committee are collaborating on a project that will show us what the children and teenagers see and perhaps feel. It will help us better understand what they are going through, what is important to them and provide us with their point-of-view... if even for a fleeting moment in time.

This is how your treatment center or parents’ group can participate in this very important project. On February 15, 2005 – International Childhood Cancer Day, we would like you to place cameras into the hands of children with cancer and ask them to take pictures of anything they like (in the out-patient or in-hospital setting). It is important to us that the children take the photos and that the photos are taken on February 15th so we can all witness what the world of childhood cancer looks like on that one day – throughout the world!

We would like you to choose the most telling and illustrative photos and email or post them to the project organizers at:

Email: through-my-eyes@kidscancercare.ab.ca

Through My Eyes: A Day in the Life of Children with Cancer Around the World

c/o Kids Cancer Care Foundation of Alberta

Suite 205, 609 – 14th Street NW

Calgary, Alberta T2N 2A1 CANADA

We must receive these photos by email or the photos (with negatives) by post, no later than March 15, 2005 so that they can be arranged for display.

These photos and the accompanying statements will become a part of a permanent collection so we will not return the photos or the text. Therefore, please make copies of them prior to sending them to us. If you need assistance in paying for the film, developing or postage, the project sponsor will pay for reasonable expenses with receipts.

The photo exhibition “Through My Eyes” will be shown at the next meeting of SIOP/ICCCPO in Vancouver in September 2005. The photo exhibition may, over time, become a beautiful published book that could help to educate, inform and publicize the status of childhood cancer throughout the world. The value would be extraordinary and it may be useful to many developed and developing countries as a form of public awareness.

For more detailed information contact the ICCCP-O-website or Christine Wandzura c/o Kids Cancer Care Foundation of Alberta (s.above).
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