

ICCCPO Newsletter

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

A note from the editors

Through My Eyes

... was the title of a very successful project of this year's International Childhood Cancer Day (ICCD). The patients in hospital were asked to take photos of their environment, such as their hospital rooms, their beds, their toys, their favourite nurse, etc. and to send those pictures to the organizing committee of the Vancouver SIOP conference. The pictures will be presented at the SIOP/ICCCPO conference in Vancouver, Canada (September 19-24, 2005, see also program on page 11). Many, many children participated. In Germany alone, about two hundred from more than thirty clinics were involved. As far as we can tell already, the photos are wonderful and demonstrate what these children consider important. The German parent initiative will be celebrating its 25th anniversary this fall and plans to present a great number of those photos taken in German hospitals (some are shown here).



"I love the ClinicClowns, because they makes me laugh"

Reactions such as the following show the importance of the International Day in the specific countries:

I am glad to tell you that this year our ICCD will take place at Los Pinos, the official residence of our President. This year, our First Lady agreed to have our reunion of more than 500 people at their residence. We are going to have 3 youngsters who have survived their disease and live happy lives to talk to the media. We are going to have full coverage about AMANC and ICCCPPO. I am very happy to tell you that after 22 years of struggle, finally this government is accepting childhood cancer as a public health problem and is working out a plan to have full coverage of all leukemias to start with... Bless you, Lupita (AMANC, Mexico).

Surviving and thriving was the theme of the ICCD 2005. Even when properly treated, childhood cancer can often have serious side effects and long-term consequences. Children have the right to qualified rehabilitation after treatment – the right to thrive. This is a very important issue for parent initiatives, since many times the former patients face numerous problems as young adults, e.g. in school, in finding jobs or getting accepted for health and life insurances.



"My play room"

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These are some of the issues addressed at the survivors meetings which have become part of the ICCPO annual meetings. This year again, survivors from all over will join to attend their own program in Vancouver as well as participate in lectures and workshops presented by ICCPO. This has added another dimension to the ICCPO meetings and is gratefully appreciated.

Better care for children in Europe

In October 2004, ICCPO joined the board of SIOP Europe in a lunch debate with members of the European Parliament in Strasbourg, France. "Europe

should take all possible measures to enhance the existing collaboration between paediatric oncologists both in the treatment and research of childhood cancers. There is a great concern that current and proposed EU legislations threaten this collaboration, and as a consequence, children," this was the warning given by SIOP Europe and ICCPO. At the debate we discussed the organisation of care, the need for collaborative international clinical trials, the draft Regulation on Medicinal Products for Paediatric Use, and what Europe can do to address these issues.

*Gerlind Bode
Marianne Naarfs-Wilstra*

**The International Childhood Cancer Day 2005
A Report from Singapore**

CCF applied for membership to be part of the ICCPO in 2004. Hence, 2005 was the first time that we celebrated the International Childhood Cancer Day in Singapore.

We took the opportunity to highlight the situation of childhood cancer in Singapore and the work that we are committed to – enhancing the lives of children with cancer and their families. Thus, our main objective of ICCD 2005 was:

To raise awareness of childhood cancer in Singapore by introducing the gold ribbon which is the official ribbon for childhood cancer around the world.

Our secondary objectives are:

- To create a memorable event for our stakeholders.
- To share more information on childhood cancer and how this illness has affected the lives of our clients.
- The healthcare situation in Singapore for children with cancer.

As this was the first time that ICCD was marked in Singapore, we wanted to involve as many Singaporeans as possible to participate in our gold ribbon campaign which ran from end Dec 2004 to end Feb 2005. The public was encouraged to show their solidarity by wearing the gold ribbon pin on 15 February 2005, the actual day of ICCD and submitting their pledge online on our specially-created ICCD web-site. Our target was to reach out to 100,000 Singaporeans who will pledge their support for our children.

Target audience

- CCF children and families
- Regular CCF donors
- Childhood CARE schools
- Employers of parents of CCF children
- Staff from the pediatric oncology wards in KKH and NUH
- CCF regular volunteers
- Employees of corporate sponsors
- General Public (Adults)

About the gold ribbon pins

The gold ribbon is the official ribbon of children with cancer worldwide, supported, recognised and promoted by hundreds of organisations and treatment centres related to childhood cancer. It was inspired by the life of Kelsey Nicole Thorsen, 1989~1996. You can read about her story at

<http://www.goldribbons.com/kelsey.html>

Internationally, the gold ribbon represents children with cancer in these and other ways:

- It is a precious metal, as our children are precious;
- It is the purity of our children's hearts;
- It is the flame of hope.

To us, the gold ribbon also represents the strength of our children and their families who have fought a brave battle with childhood cancer. This source of strength is "cast" from the support of many people who have contributed in their various capacities: the medical team, our social workers, sponsors and donors, volunteers and schools.

Pin distribution

Staff at the CCF main office was split into two teams to distribute the pins at two venues: Orchard Road (with The Body Shop staff) and Shenton Way (outside Raffles Place MRT station with two other ad-hoc volunteers). Staff at National University Hospital also helped to distribute the pins at the hospital lobby, while the pins were left the clinics at KKH Women's and Children's Hospital for visitors to pick up.

We planned to distribute the pins to the public through various channels, mainly:

- online orders (for more than 100 pins)
- placement of pins at different distribution points at the shops
- bulk orders from corporate employees
- public call enquiries (from our various communications channels)

Many companies supported us as well as schools (in total: 43 companies, 13 schools, 3 healthcare organisations, 3 community organisations). Our CCF volunteers also helped to coordinate some of the distribution to the restaurants and shops.

Public awareness

A lot of media coverage supported us. We created our own ICCD website with information for the public on what the event is about, what they can do to help, where to get the pins and stories of our children (with a message board). It proved to be an effective form of communication to the public. Three email alerts were sent out as well to inform our contacts about the event (end Jan, 7 Feb and 14 Feb). So far, it is the most effective "call-to-action" channel.

About 120 posters were produced and given out to all shops and companies, 14,000 Bookmarks were produced and placed in taxis and other distribution points. We also sent letters to past donors and CCF parents, with an enclosed employer survey form to gather feedback from CCF parents on current employment situation for them.

Ward activities for children staying at KK Women's and Children's Hospital

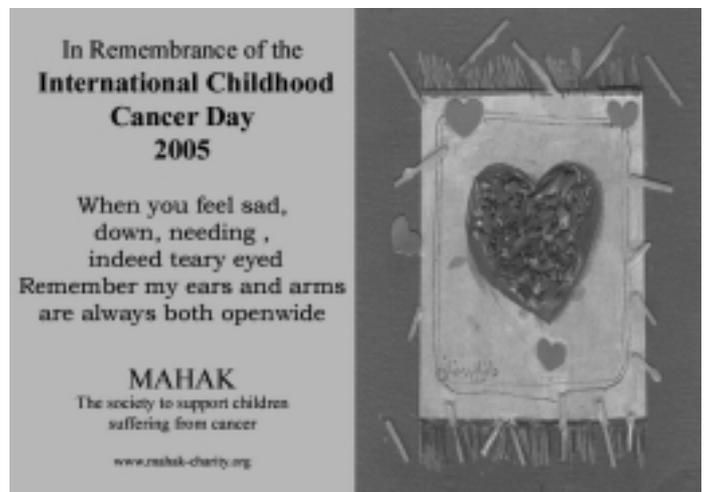
A group of undergraduate students volunteered to organise and execute a ward activity for the children with cancer at the hospital. They played bingo in the morning and the healthcare professionals who worked with the children, joined them for a lunch reception thereafter. We also organised a CCF lunch-time workshop on "Long term side effects of cancer treatment: what you need to know" for parents.

Conclusion

Despite the intensive tsunami appeal in late December 2004 to mid January 2005, Singaporeans continued to show their support for local causes and orders for the gold ribbon pins poured a few weeks before ICCD. It was heartening to see the support from different individuals, volunteers and companies, in helping to raise the awareness of childhood cancer through the pin distribution.

All in all, we met our objectives for the event and distributed 100,000 pins to the public. However, more can be done in the area of raising childhood cancer education in Singapore. Hence, we aim to include more awareness fringe activities and implement a more effective communications strategy for ICCD 2006.

*Evangeline Goh
Public Education Officer
Children's Cancer Foundation, Singapore*



Card commemorating ICCD in Iran

ICCD in Bangladesh

We are very pleased to inform you that Children Leukaemia Assistance & Support Services (CLASS) observed the International Childhood Cancer Day '05 with due solemnity. In observance of the day in a befitting manner, CLASS drew up a two day long program on the 15th and 16th February. On the first day, medicine and gifts were distributed to the cancer stricken children under treatment at Chittagong



Medical College Hospital. A counseling and discussion program with related physicians and parents and amusement programs for the children was also organized on that day.

On the second day, a colorful rally was brought out from Circuit House Premise. Over 500 students of various schools of the city, Rotarians, Rotaractors, Boy Scouts and Girls Guides participated. The rally paraded through the main through-streets of the city. Leaflets, banners, festoons having awareness slogans were distributed among the public. This unparalleled and colorful rally could caught the attraction of city dwellers which was led by the honorable vice chancellor of Chittagong University, Professor A. J. M. Nuruddin Chowdhury and the principal of Chittagong Medical College Professor Dr. Chowdhury B. Mahmud.



In observance of the day, CLASS published colorful posters and leaflets in corporate public awareness issues which were distributed among the students and guardians. CLASS also organized publications of articles focusing on the topic of childhood cancer in local newspapers to raise the public awareness.

*Osman Gani Mansur
CLASS, Chittagong*

Leontien Kremer

The development of the Cochrane Childhood Cancer Review Group

Presentation from ICCCPO-Conferences

In the second half of the last century, clinical trials led to major developments in pediatric oncology. Approximately 600 randomised trials have been performed together with many non-randomised controlled trials. Healthcare providers in pediatric oncology face a serious challenge to keep up-to-date with the latest evidence. Research is being published every day, all over the world. Scientific summaries of evidence, systematic reviews, can help healthcare providers to keep well informed.

In 2004, the Emma Children's Hospital of the Academic Medical Centre in Amsterdam, the Cochrane Cancer Network and the Dutch Cochrane Centre initiated the set-up of a Cochrane Childhood Cancer Review Group (ChCRG) The Cochrane Childhood Cancer Review Group will form one of the Collaborative review groups within the Cochrane Collaboration. This review group will support the production and dissemination of systematic reviews on the effects of interventions in children with cancer concerning: prevention, treatment, supportive care, psychosocial care, palliative and terminal care, nursing care and late effects of treatment. A Cochrane review group focusing on systematic reviews in childhood cancer was lacking. Official registration of the possible Cochrane Childhood Cancer Review Group within the Cochrane Collaboration is expected in 2005.

The Cochrane Collaboration (www.cochrane.org) is an international non-profit organization, dedicated to produce up-to-date, accurate information about the effects of healthcare readily available worldwide. In 2004, more than 11,500 people were working within the Cochrane Collaboration in over 90 countries, half of whom are authors of Cochrane Reviews. Most do not receive a payment for their Cochrane work as they are committed to its purpose.

The main activity of the Collaboration is to develop Cochrane systematic reviews of the strongest evidence available. Clinicians, parents and patients can be assisted in making well informed decisions by using a systematic review. A Cochrane systematic review is a systematic, up-to-date summary of reliable evidence of the benefits and risks of healthcare interventions. The Cochrane systematic reviews are published electronically within the Cochrane Library (www.thecochranelibrary.com) and are freely accessible in short versions.

On February 2nd 2004, 60 interested and enthusiastic people, including paediatric oncologists, nurses, methodologists, and parents of children with cancer

from different countries attended the exploratory meeting of the Cochrane Childhood Cancer Review Group. International speakers highlighted

several organisational aspects for the new review group, the need for systematic reviews for research and for clinical practice, and highlighted future directions of systematic reviews as a research discipline.

The main activities of the Cochrane Childhood Cancer Review Group will be

- to support the production and dissemination of systematic reviews on the effects of interventions in children with cancer
- to maintain a register of existing clinical trials in children with cancer
- to distribute knowledge making of well-informed decisions about interventions in children with cancer via website and courses.

Before the SIOP meeting in Vancouver, the Cochrane Childhood Cancer Review Group will organise a Cochrane systematic review course for future authors of reviews. Several reviewers are already active in performing a systematic review. More than 100 persons such as paediatric oncologists, nurses, methodologists, parents of children with cancer and survivors have shown interest in the group and are willing to contribute to systematic reviews in childhood cancer. Eighteen people will form the editorial board: M. Bernstein, G. Bisogno, B. de Camargo, H. Caron, F. Doz, T. Eden, C. Eiser, F. Gibson, N. Graf, L. Kremer, P. Kurkure, N. Langeveld, S. Lipshultz, D. Moher, R. Pieters, R. Pinkerton, M. Stevens, M. van de Wetering.

Involvement of parents, patients and survivors in the Cochrane Childhood Cancer Review Group will be really important to stimulate systematic reviews relevant for patients and to produce clear summaries of systematic reviews! If you would like to have more information or if you would like to participate in this new development please contact Chcrg@amc.uva.nl

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*This Paper was presented at
the ICCCPO annual meeting in Oslo, 2004.*



Faith Gibson

Striving for normality: the experience of cancer related fatigue in young people

Through the generous support of The Lisa Thaxter Trust a group of nurse researchers in the United Kingdom has recently completed a study on the impact of cancer and treatment on adolescents. The specific focus of the study was on cancer-related fatigue. In order to find out whether the youngsters had experienced this symptom, we decided that we needed to know how they felt they managed their 'normal' day to day activities and, if they identified fatigue as a symptom, to discover if they had developed ways of coping with it. A range of different methods of collecting data were used, including interviews, diaries (both paper and electronic) and discussion groups. We included adolescents who were currently receiving treatment for cancer (8), those who were in early remission (7) those in late remission (22), and a group who had not had cancer (20).

The adolescents on treatment reported fatigue to be overwhelming. They perceived it had a significant effect on their physical, psychological and social well-being. These effects were felt to place an extra burden on them whilst they were striving to achieve normality in their lives. For example, consider this account by Caroline who is receiving treatment:

Caroline started treatment two months ago and is currently still going to hospital for radiotherapy. She lives at home and goes to college for just 6 hours a week to do her one A level in Art. Prior to

her cancer, she was doing 4 A levels and went dancing once a week and rode and looked after her horse. Her treatment and recovery are having a significant effect on the way she is able to lead her life. However, she does not voice a particular concern about this. Fatigue for Caroline occurs in both her body and her mind simultaneously. If her body feels tired then so does her mind. Activities such as walking the dog, which previously she could do easily, now cause both body tiredness and aching knees. Fatigue in her mind often came from school work, where she found it difficult to concentrate. Being with other people, and where there was a lot of chatting and conversation occurring also tires her mentally and physically.



Striving for normality was also a feature of adolescents who had completed treatment. For adolescents who were experiencing ongoing health problems and worries, fatigue appeared to play a significant role. For others, fatigue was not a feature of their lives and they identified themselves much more closely with their peer group in the activities and social lives they

Table 1 What might help?

Health Care Professionals	Adolescents and parents/carers
Prepare adolescents for all potential side effects of therapy	Prepare for change in dependence
Information and education to feature throughout the course of treatment and care	Identify and mobilise what helps
Acknowledge the presence of fatigue	Respond to non-verbal expressions of emotional fatigue
Prepare to anticipate unpredictable nature of fatigue	Encourage a balance between rest, sleep and activities
Provide opportunities to talk and express feelings	Plan time-limited activities
Assess symptoms, including fatigue	Encourage maintenance of social contacts e.g. email and internet
Identify normal pattern of activities for the adolescent	Acknowledge life-changing effect that cancer may have
Identify and mobilise what helps	Prepare school/employers for alterations in activity and concentration
Refer to other professionals as appropriate	Provide opportunities to talk and express feelings
Identify strategies to support reintegration to normal life	Identify strategies to support reintegration to normal life.

shared. Adolescents off treatment varied widely as to how they thought cancer and its treatment had affected their lives. None of the adolescents reported the debilitating and extreme fatigue that those on treatment described. In contrast, for adolescents who had not had cancer, whilst extreme levels of tiredness would appear to be a common feature of their lives, they saw it as a normal expression of a busy life. This did not necessitate a change in lifestyle and was not associated with any ongoing health problem. Life for these adolescents seemed to be a constant balancing act between school, home life and social activities.

What was most striking in our study was the difficulty adolescents had in separating the symptom i.e. fatigue, from the overall experience of cancer. Uncertainty and anxiety were featured in many of the adolescents' accounts alongside strategies used to manage symptoms and their cancer experience. Fatigue was accepted as a consequence of having cancer. Therefore from our own study and other research from the USA and Europe it would seem to be important that doctors and nurses give information about fatigue to children and adolescents at the time of diagnosis, when they are being prepared for treatment side effects. At the same time, we would encourage families to seek more information about this symptom from doctors and nurses. Families might also like to think about noting/recording the experience of fatigue and how it affects their child and the whole family so that the information can be shared with any of the professionals providing ongoing care. Although adolescents in our study had found ways to cope with the symptom, usually involving taking more rest and sleep, it is still too early for us to be able to describe to fami-

lies particular ways of effectively managing fatigue. We have however, made some suggestions of what might help in Table 1: adolescents and parents might like to think about these and share their thoughts with health care professionals they meet.

We need to find ways to help adolescents gain control of their symptoms, to adjust to a cancer diagnosis and be successful in reaching their developmental milestones that will enable them to lead a fulfilling life. For that reason, further research is required to develop a fuller understanding of cancer-related fatigue and ways in which to help and support adolescents to effectively manage their experiences of this symptom.

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This article reflects the content of a paper delivered at the SIOP/ICCCPO Meeting, Oslo (Norway), 2004

Marianne Naafs-Wilstra

Supportive care for children with cancer: a national consensus

Children and adolescents with malignancies are referred to a paediatric oncology centre where a multi-disciplinary team can attend to both medical and non-medical needs. In such a tertiary centre, initiation of therapy and ongoing monitoring of treatment response occurs. Key elements are continuity of care, familiarity, and trust from diagnosis through all stages of care, including palliative care and long-term follow up of survivors.

Children and adolescents have the right to stay at home and live a life as normal as possible and disruption of family life should be prevented as much as possible. Shared care, with the involvement of the family doctor and the general hospital near the place where the family lives, is a solution. Provided that ongoing quality of care is guaranteed some selected compo-

nents of care can be equally well provided in the community. Often these are components of supportive care. When a child or adolescent cannot be cured, he/she should be allowed to die at home, unless the parents and the patient decide otherwise. For those families who decide to have their child die at home, continual medical and psychosocial support should be insured. In the palliative phase families should at no point feel abandoned by the professional caregivers.

The importance of supportive care

During the last decades combined and improved treatment modalities have gradually increased survival



rates for children with cancer from less than 10% in 1940 to around 73% at present. Although surgery, chemotherapy and radiotherapy account for this 180° turn, advances in supportive care allowed the reversal to occur. Without supportive care there would have been little progress in the major therapeutic disciplines. Children would have died from complications and infections caused by the intensity of the treatment. Supportive care made it all possible.

Supportive care comprises multiple modalities such as nutritional support, mouth care, toxicity monitoring, antibiotics, early treatment of fever, immunizations, prevention and treatment of emergencies, blood products, pain management, growth factors, anti-emetics, vascular access, psychosocial care, home care, palliative and terminal care, etc.

With the intensification of the therapy, the need for adequate supportive care is of utmost importance to maintain the high percentage of survival. Driven by innovative and ever more aggressive therapeutic approaches, supportive care must be constantly intensified and improved.

With the increase of the survival rates of children with cancer, the quality of life during and after treatment is displacing cure as the paramount objective. It is also this shift in emphasis that makes supportive care as important as surgery, chemotherapy or radiotherapy.

The need of a formalised approach

Outreach programmes have many advantages: family life remains more or less intact, there is less travelling so less expenses, and patient and parents report the special attention in the community where a child with cancer is unique. But:

- 1) The family has to deal with more caregivers. Often very shortly after diagnosis the child is referred back to the hospital in the community. The family has hardly overcome the first shock when they have to deal with new caregivers. New people, different approaches. It takes time and energy to get to know these new people involved in the treatment of their child, and to build a trustful relationship with them as well.
- 2) Even the slightest difference in procedures can cause uncertainty, insecurity and concern. A different type of needle for the Porth-a-Cath or for a capillary sample, a different sequence for a drip, wearing gloves or not, a venous puncture instead of a finger prick, waiting in the general waiting room with a risk of infection, a doctor who is nervous and thus shows he doesn't often see children with cancer, a lab assistant who doesn't give the child the choice in which finger it will be poked, results of blood samples that aren't given within 30 minutes like in the centre but only the next day, no possibilities to stay with the child during the night ... all factors that can influence the family's trust.

- 3) A different approach in supportive care measures can cause enormous stress with child and parents. The how, when and where of anti-emetics, antibiotics, management of fever, transfusions, nutritional support, pain management etc. are sometimes not in accordance with the centre. The same applies to the daily regimen: is the child allowed to go to school, to swim, to eat salads, ice-cream, soft cheese, to have visitors, pets, to go to the cinema, the zoo, etc.
- 4) Medical information given by the general paediatrician can be different and even contradictory due to lack of expertise or lack of communication with the centre. No wonder parents start questioning the quality of care: do they here know as much as in the paediatric oncology centre? Is my child safe and in good hands?

How do we make sure that ongoing quality is guaranteed? How can we - during the entire treatment process - support families in such a way that they are convinced that the child gets the best possible care, whether it is in the paediatric oncology centre, the regional hospital or at home? What are the requirements to make supportive care in the community a success?

Uniformity in supportive care

The uniqueness of childhood cancer care requires an organised and formalised approach, the development of special knowledge and expertise in community caregivers and a commitment to ongoing education.

Though today no one will question the important role of supportive care for children with cancer, only a few clinical studies have been performed in this area and standards of care are far away. The influence of supportive care as a variable on clinical outcome could be as great or even greater than that of a specific therapeutic manipulation. This speaks for an adoption of some uniformity in supportive care measures in the conduct of cooperative studies.

Uniformity and a common approach in supportive care is also important to prevent distress among patients and parents.

National consensus

Four years ago, the Dutch Childrens' Cancer Study Group (SKION) formed a task group Supportive Care with the purpose to develop national guidelines for supportive care for children with cancer.

The group consisted of representatives from the five paediatric oncology centres, the two paediatric bone marrow transplant centres, the paediatric oncology nurses group and the parent organisation (VOKK). The task group developed a Handbook Supportive Care, based upon evidence (if any) and on national consensus. The input of the Parent Organisation (VOKK) has been indispensable in the sense that their representa-

tive could identify the questions, needs and uncertainties of parents and be their voice in important areas like pain management, home care, palliative and terminal care, psychosocial care etc. The book will be published mid 2005 and be sent to all paediatricians that are involved in the treatment of children with cancer. This is a good example of a formalised, uniform approach.

Conclusion

To make supportive care in the community succeed, it is essential that the patient cooperates. Parents need to be educated about possible problems, need to know

when to get professional help, and whom to call. A consistent policy and national protocols for supportive care are essential to gain the trust of the patient and his/her parents. Finally effective and fast communication between the different health care systems and the parents is a condition sine qua non.

Dr. Marianne C. Naafs-Wilstra, executive director Childhood Cancer Parent Organisation VOKK, The Netherlands, ICCCPPO board member

This paper was presented at the tenth anniversary meeting in Valencia (Spain), May 2204.

News from SIOP

The focus of our attention in the SIOP Scientific Committee and the Board right now is on review of the abstracts submitted (deadline March 1st 2005) for the 37th Congress of SIOP to be held in Vancouver between September 21st and 24th 2005. One of the exciting features for myself as President and of course the Board of SIOP in general is the way in which increasingly we are working closely with parents and survivors to develop complementary programmes at our annual meeting. This year has been an even more close joint effort because of the Through My Eyes photographic competition and a number of the symposia at the meeting, which are really held jointly between SIOP, The International Nursing Group affiliated to SIOP and ICCCPPO.

Of particular interest to all of the groups is the development of outreach to the estimated 80% of children worldwide that don't receive adequate care for their tumours or any treatment at all. As a joint effort we have been developing twinning programmes focussing very much on how parents organisations can influence local populations and politicians much more effectively than ever we can. Hence the huge strength of our collaborative activity.

SIOP has signed up to in the production of a mission statement trying to persuade WHO and all other relevant regulatory authorities to put cancer drugs, particularly for children, on the essential drugs list with a consequent reduction in costs, regularisation of supply throughout the world. Our desire is that therapy should be used in locally produced relevant protocols in specialised units to reduce the risks of inappropriate therapy and the waste of precious agents.

There is a huge amount left to do with reference to both population and professional training and education. For 2005 the Board have commissioned a sub committee of the Scientific Committee chaired by Bharat Agarwal to look at the whole issue of an education and training programme starting with our annual meeting but moving on from there to address the whole aspects of our contribution to training worldwide.

To achieve everything we want to do will cost more money than we currently have available or indeed are able to raise as any form of profit from our annual meetings. So I have started a process of looking firstly at what the vision for SIOP is as seen by its committees and membership in general. When we are all agreed on what we want to achieve in the long term we will produce a mission statement and then start to raise the appropriate funds in a variety of ways in many different countries to try to deliver on our aims and objectives. So we are living in exciting and difficult times but if we don't face up to these challenges we will not move forward and meet the needs of children worldwide. ICCCPPO and the continental SIOP branches must begin to work more closely together to deliver a coherent activity worldwide.

I personally look forward to meeting as many members of ICCCPPO who are able to come to Vancouver. In the meantime can I pass on to all of you through the newsletter all the very best of wishes for a successful 2005 and to thank you on behalf of the SIOP Board for all that you are doing to advance the cause of the best care for children worldwide.

*Professor OB Eden,
Chair SIOP*

Two Worlds – One Family:

a round-table organised by ICCCPPO and SIOP (Oslo 2004)

At the recent SIOP/ICCCPO-meeting, a round table forum was organized to develop guidelines for Twinning Projects. It was stated that twinning is an important subject affecting more than 200,000 children with less than best treatment. The discussion concluded with a number of statements, which will be integrated into the guidelines.

Essential elements for twinning:

- a skilled, full-time program leader
- a community support group
- long-term institutional commitment
- a multidisciplinary approach

Links are created on the base of

- long-term relationships between people of different countries
- support from parents groups
- cancer funds
- palliative care projects

Assessment of needs:

- create templates for assessments of units, institutions
- request visits in advance and declare purpose of visit

Priorities:

- start with frequent tumors easy to treat
- do feasibility studies: use adapted protocols
- train personnel to attain high standards of care from onset
- organise independent supervision

Affordable treatment

- contact IDA, P.O.Box 37098, 1030 AB Amsterdam, the Netherlands (info@ida.nl;www.ida.nl) for certified drugs and utensils
- supervise transport through customs (loss, delays), collection (theft) and distribution to parents (without charge)

Training priorities

- train always 2 per area and use them as future local trainers
- do not allow rotation (e.g. of nurses) as skills are lost
- provide periodic up-date training

Role of parents:

- mobilise resources
- provide advocacy and local empowerment
- support survivors and their families

Awareness at the primary care level:

- tell professionals, parents, media and TV that childhood cancer is curable
- promote St. Silvan's early warning signs
- organise triage and palliative care in the periphery

Contributors of this discussion:

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Responsible Coordinator for ICCCPPO: Geoff Thaxter (Vice-Chairman) for SIOP: Hans-Peter Wagner (Chairman, PODC Committee)



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A Bridge for Life

Twinning between Italy and Paraguay



Paraguay is a South American country with a population of 5.5 Mio. The country which is characterized by a continuous instable political situation, suffers from a weak economy and a consequently very poor socio-economical situation with growth problems in many sectors, including those of education and public health.

The health service does not have access to sufficient funds to buy chemotherapy drugs, which therefore must be paid for by families who rarely have the means to support the therapy.

Each year about 140 new cases of childhood cancer are diagnosed, and the mortality rate is very high (although it is impossible to collect exact data). This is partly due to abandonment of treatment because of the difficult social-economic conditions of the family, but it is also caused by the high incidence of infections in medical structures where it is difficult to respect the hygienic and sanitary norms necessary to cure patients affected by onco-haematological diseases.

Because of this situation, we feel that the priorities of the scientific community of developed countries must include the absolute necessity of sponsoring programs in paediatric oncology in countries with little resources. Our project "A Bridge for Life" was founded in 1999, inspired by an idea of Prof. Fausta Massola, at that time director of the Pediatric Oncology Clinic of the Modena Hospital in Italy. The object of this project is to transfer to underdeveloped countries the most recent medical and scientific knowledge available, creating at the same time the social conditions necessary to give these little patients a better probability of being cured of their illness and assist their families through this period.



The aims of the project:

- Medical training;
- Supplying of medical equipment;
- Renovation of the hospital environment;
- Concrete aid to the families of the sick children (construction of a community home for the families);
- Financing for chemotherapy treatment (long distance aid)



Activities

The Paraguay project took off in September 1999 with the arrival of a pediatrician at the Modena Hospital Pediatric Oncohematology Clinic for a period of formation that lasted two years, dedicated to the acquisition from a medical team of all methods currently used in the cure of childhood cancer patients in Italy.

At the same time that this training of health operators was going on, funding was provided for the acquisition of hospital furnishings for the day-hospital of the "Hospital de Clinicas" of Asuncion. In February 2001 we contributed to the construction of the "Hotel-Home Fausta Massola" which offers hospitality to the families of sick children who live far from this center of therapy.

In May 2002, ASEOP provided hospitality to a second doctor from the Hospital General Pediatrico "Ninos de Acosta Nu" of Asuncion, for a medical-scientific exchange program involving the Transfusion Service of the Modena Hospital with the aim to organize a blood donors centre in Paraguay in collaboration with AVIS (the Italian blood donors association).

In November of the same year, hospitality was provided for both a surgeon and a nurse to acquire specific training in the pediatric oncohematology field. In 2003 a second nurse arrived for a training here in Italy for one month followed by another paediatrician in 2004

In March 2002 and 2003 we sent a container of chocolate Easter eggs to MITAI, for a promotion and fund raising campaign, hoping to improve the financial independence of the parents' association. Then, a second container was sent, carrying a third, last generation, CAT scanner (no longer used by the Institute of Biomedical Research at Empoli), together with a used ambulance donated by the Mirandola Health Care District, a sterilizer, two computers and various sanitary material.

2002 marks the foundation of MITAI, a parents' organization that operates in Asuncion with the same aims of our association; in this way another important stepping stone was laid down. MITAI began its activity with a fund raising campaign, selling the chocolate Easter eggs provided by ASEOP, which, together with a contribution from the Modena Town Council, served to finance the chemotherapy treatment of several children.

Due to the ever growing number of children with cancer admitted to the General Pediatric Hospital "Ninos de Acosta Nu" the building had to be enlarged. We helped in the funding of a larger the Paediatric Oncohematology Ward, which was inaugurated in our presence in January 2003 during our visit to Paraguay.

In that occasion the President of ASEOP met with the new Health Minister, Josè Mayans, with the General director of the Pediatric General Hospital "Ninos de Acosta Nu", Pedro Guanes, with whom we are currently collaborating, and with the members of the new parents' association MITAI, with whom we are trying to create a strong bond in order to help in bettering the social conditions of the families during their childrens' period of therapy.

ASEOP wishes to underline the importance of creating a data bank as soon as possible, in order to monitor the results of all of the activities that have to do with curing the children.

Towards the end of the year 2003, we activated a new program of long distance aid for the financing of chemotherapy treatment for children with leukaemia, and we have already found 25 private sponsors and schools.

Lastly, the volunteer association "La nostra Mirandola", which collaborated in this project, has financed the construction of a community home in the hospital area, to offer hospitality to the families and the children undergoing therapy at the hospital. This guest house will soon be opened.

It is our hope that our project with Paraguay "A Bridge to Life" will give us together with other collaborating organizations and institutions the possibility to expand the benefits of scientific progress to these countries, activating aid programs for the promotion of the right to health of all children in the third world countries who are living the drama of cancer.

*Valeria Casadio
ASEOP Onlus, Modena, Italy*

ICCCPO-Parents and Survivors – Meeting

Together with SIOP Vancouver (Canada), September 2005

Developing Countries Working Dinner Monday, Sept. 19th

Board members representing the four developing regions of the world will facilitate this working dinner. It is provided free of charge to parent and survivor group leaders from developing countries - To register, please contact Dan Mornar at dmornar@cw.bc.ca no later than July 31, 2005. (There will be no charge for this dinner meeting, thanks to our generous sponsors.)

Pre-Education Day, Tuesday, Sept. 20th

This all day seminar will be provided free of charge and will feature topics on fundraising, organizational development and volunteer management - all facilitated by professionals working in these areas. It is open to all parents and survivors and they must pre-register with Dan Mornar at dmornar@cw.bc.ca by July 31, 2005. (There will be no additional charge for this all day seminar, which includes lunch, thanks to our generous sponsors.)

Annual Meet & Greet Tuesday evening, Sept. 20th

This event will immediately follow the education seminars and is open to parents, survivors and invited guests. Please remember to bring a specialty of your country to this reception, either a food or a beverage. Please remember that Canada Border Services Agency will not permit the importation of any food item that contains meat, eggs, dairy products, fresh fruit or vegetables. (There will be no charge for additional food and beverages that will be served at this event, thanks to our generous sponsors.)

Wednesday, Sept. 21st

ICCCPO Opening Ceremonies

Invited Speakers • Abstract Speakers
topic: Non-Traditional Recreation Programs
Joint Session with Doctor, Nurse, Survivor, Parent
SIOP Opening Ceremonies (The cost is included in the SIOP registration.)

Thursday, Sept. 22nd

Abstract Speakers - topic:
Programs for Siblings, Grandparents and Extended Family

Abstract Speakers - topic:
Palliative Care and Bereavement Programs
ICCCPO Interactive Board Session
ICCCPO Annual General Meeting - members only

ICCCPO Annual Dinner - Parents, Survivors and Invited Guests only and delegates must pre-register with Dan Mornar at dmornar@cw.bc.ca by July 31, 2005. (There is no charge for this dinner thanks to our generous sponsors.)

Friday, Sept. 23rd

Joint Sessions with Doctors, Nurses and Psychologists

SIOP Annual Farewell Reception - (You must register and pay with SIOP registration at a cost of \$60CDN per person.)

Saturday, Sept. 24th

Joint Sessions with Doctors, Nurses and Psychologists

Should you have any questions about the arrangements this far, please contact me at the address below.

Christine Wandzura, M.S.M., CFRE
Chair, 2005 Vancouver Conference
c/o Kids Cancer Care Foundation of Alberta
Suite 205, 609 - 14th Street NW
Calgary, AB T2N 2A1
Phone: +1-403-216-9210 ext 221
Fax: +1-403-216-9215
email: wandzura@kidscancercare.ab.ca



Preliminary Schedule for the ICCCPD/Survivors – SIOF Meetings Vancouver, Canada -- September, 2005

Time ↓	Sunday Sept 18	Monday September 19	Tuesday September 20	Wednesday September 21	Thursday September 22	Friday September 23	Saturday September 24
	WHHO →	Parents Survivors	Parents Survivors	Parents Survivors	Parents Survivors	Parents Survivors	Parents Survivors
Early Meeting	VCEC Room: 7 Board Meeting Board Room for 10 people	VCEC Room: 10 Survivors Committee Meeting Board Room for 6 people	VCEC Room 12 Pre-Ed Day Priority Setting, Benchmarking & Evaluation Sponsored by: KCCFA	VCEC Room 11 Operating Ceremonies Room 11 & 12 Tim Edon, SIOF Simon Lala, ICCCPD Anthony Penn, Survivors David Steens, Childhood Cancer Foundation, Canada	VCEC Room 11 Abstracted Speakers: Sibling, Grandparents And Extended Family programs	VCEC Room 7? New Executive Committee Meets	VCEC Various Joint Session with Nurses; Consent to treatment and care
Break	Nutrition Break	Nutrition Break	Nutrition Break	Nutrition Break	Nutrition Break	Nutrition Break	Nutrition Break
Late Morning	ICCPO Board Meeting	Survivors Committee Meeting	Pre-Ed Day Volunteer Management	Invited Speakers	Abstracted Speakers: Palliative Care and Bereavement Programs	Survivors Learn for Social Activity	Joint Session w Psychosocial Aspects of managing adolescents w cancer.
Lunch	Lunch w Survivors	Lunch w Board	Box Lunch Brought In	Lunch on your own	Lunch on your own	Lunch on your own	Lunch on your own
Early After-noon	ICCPO Board Meeting	Survivors Committee Meeting	Pre-Ed Day Fundraising Developed: Topic: TBA Developing: Topic: TBA	Non Traditional Recreation Programs & Survivor Programs	ICCPO Interactive Board Session	Joint Sessions: How to communicate risk	Workshop-Symposium Twining Programs
Break	Nutrition Break	Nutrition Break	Nutrition Break	Nutrition Break & Media Launch of photo exhibit Through My Eyes	Nutrition Break	Nutrition Break	Nutrition Break
Late After-noon	ICCPO Board Meeting	Survivors Committee Meeting	Pre-Ed Day Governance	Multidisciplinary session with doctor, nurse, parent, survivor. Topic "The impact on your life of being a childhood cancer survivor."	ICCPO Annual General Assembly	Joint Sessions with Nurses, PODC and psychosocial None identified yet	Joint Session with doctors. Non-conventional therapies
Evening Events	arrive in time to have dinner together	Developing Countries Regional Committee Working Dinner 17:00-21:00 Location: Room 417 VCEC Sponsored by: KCCFA	Meet & Greet 18:00-21:00 Location: Chan Centre Sponsored by: Childhood Cancer Foundation of Canada	SIOF Opening Ceremonies Location: VCEC	ICCPO Annual Dinner Location: Dinner Cruise Sponsored by: BCCCPA	SIOF Annual Dinner Pre-purchase of dinner tickets required. Location: VCEC	Dinner on your own

VCEC: Vancouver Conference & Exhibition Centre – located at Canada Place; ICCCPD/Survivors Hotels: to be determined; Meet & Greet: Chan Centre (to be confirmed)



To be Part of ICCCPPO – Means to be Part of the World

Living in the current times makes it very hard to hit the headlights unless our business activities relate to trade, politics or top art performance. Different humanitarian organizations, just like other non-governmental organizations, hold a side position, not being paid too much attention. The everyday fast pace of living does not leave too much space for humanitarian activities up till the moment when out of a blue someone is struck by a personal tragedy. Even then, many people try to escape the truth, to solve the problems on their own, in the best possible way, keeping it to themselves, not sharing their anguish with anybody. Others, quite on the contrary, realize they are not the only ones undergoing rough times, facing the problem that befell them; they welcome every conversation.

There first Associations of the parents of the children with malignant diseases was founded in 1991 in Serbia and Montenegro. These were the times when the war broke out on the grounds of ex-Yugoslavia, consequently resulting in many other troublesome problems, with almost no possibility to be solved.

In 1995. we became an ICCCPPO member and tried to participate and follow annual meetings, but it was of short duration. Daily life activities became too hard and there were few that had the possibilities, strength and energy to involve actively in the issues of the children with cancer and their families.

Since 2002, we have reinitiated our meetings and with great efforts succeeded in attending the annual meetings of SIOP and ICCCPPO. The referred meetings had beneficial effects, a kind of vitamin injection, following many years of isolation. We were amazed at the latest achievements and the things that parents managed to do for their children so as to help them win their rights; ICCCPPO has grown into a really large and powerful organization. Recollecting individually organized parents groups that were just at the beginning of their activities in 1994-1995, we were very surprised at their latest achievements and successful outcomes. The fact is that many of the referred organizations come from developed countries but, still, there is a large number of the organizations coming from poor and undeveloped countries!

The said fact gave us the strength and belief that with the support of ICCCPPO we can achieve our targets as well. It was just like that; little by little, at a rather slow pace compared to our wishes that we still managed in a two-year period to accomplish more than it was achieved in a previous 10-year period. Permanent internet communication, available information and, first of all, personal contact contributed towards the possibility of constantly updated information, helped



Irina Ban (front)
with volunteers

us to learn to define priorities, to know where to start and how to finish, how to communicate with the media, how to communicate well and positively with medical staff, to establish the cooperation with governmental authorities etc.

Regardless of the fact that everything was achieved through persistence, hard work and great enthusiasm, it is of material significance that we were greatly supported by ICCCPPO members. It makes a difference when we call for support and represent ourselves as the members of one international organization. It means we are not alone, there is somebody working on our behalf and for the perspective - we are persistently pursuing; this is the perspective shared by the parents all over the world; it means we are a part of a large international organization with clearly defined and set targets and plans.

The thing that greatly supports our credibility is that ICCCPPO has established a close cooperation with SIOP; it seems to me it is the joker that works best of all in the situation when we are faced with unconcern in some medical circles. Our last action, photo project titled "Through My Eyes" enjoyed great success thanks to, among other things, the fact that it makes a joint project of SIOP and ICCCPPO so that we were given a complete freedom to create project.

The Minister of Health of the Republic of Serbia was pleasantly surprised by the fact that there is a world team work coordinated by and between physicians and the parents of ill children as well as that the referred cooperation is of a high level. He read carefully both the last issue of the Newsletter and "10th Anniversary of ICCCPPO" and gave a public recognition and praise to us- acting in the position of home parents' association and our physicians rated highly our jointly planned actions and international activity.

All the above mentioned and many other things proof once more that material support and help are not the only things that matter: moral support is of much greater importance as well as the support of the whole world in general since ICCCPPO is really THE WHOLE WORLD!

*Irina Ban, March, 2005
Belgrade, Serbia and Montenegro*

ICCCPO affects ASHIC activities

ASHIC Foundation has been operating since 1994 - started by the bereaved parents of Ashiq Choudhury, who passed away when he was only three. Its main goal has been to serve children living with cancer in Bangladesh, in any way possible. Social awareness, private and public sources of funding for childhood cancer are limited in Bangladesh and as such ASHIC activities have been growing steadily but slowly.

Mrs. Salma Choudhury, Chairperson of ASHIC Foundation started attending ICCCPPO conferences in 1999 and ASHIC became a full member of ICCCPPO in the same year. Through her experiences and the contacts Mrs. Choudhury has made over the years, the range and quality of the ASHIC programs have improved. Also, through increased joint promotional opportunities on ICCD and at the SIOP conference held in Bangladesh in 2004, awareness about ASHIC activities is now higher both locally and internationally.

This makes implementation of new projects easier.

Another exciting door that has opened for ASHIC through ICCCPPO is the potential of a twinning program to eventually offer palliative care to cancer-affected children in Bangladesh. ASHIC has been working with Geoff Thaxter of the Lisa Thaxter Trust in UK, another ICCCPPO member, to jump-start this program, and both parties have made forward progress. This will be a wonderful development for the children living with cancer in Bangladesh because currently there is no form of medical comfort that is available to the terminally ill.

Since its association with ICCCPPO, ASHIC has gained momentum in its work, developed an incredible network of people who are willing to help the children in Bangladesh, and formed some lifelong friendships that transcend cultural and geographical differences.

*Salma Choudhury
Chairperson, ASHIC*

Regional Group Reports

4th International Week for Children with Leukemia



Children with leukemia from different nations have been gathering in Turkey for the last three years at the International Week for Children with Leukemia (IWCL) pioneered by LOSEV, an organization that works worldwide.

We, as LOSEV-Children with Leukemia Health and Education Foundation, wished to bring together children with leukemia from different nations, in order to emphasize the reasons for leukemia, to increase the success rate of treatment and attract people's attention all around the world to leukemia disease. Children who share the same faith and face the same obstacles, embraced each other to show that "They are not alone".

Previous International Weeks for Children with Leukemia had given us the opportunity to bring children with leukemia from 25 different nations to our country. Children shared their stories, cultures, experiences and the problems they face in their own countries, and worked together to create solutions to these problems, while having a great time and visiting popular tourist, historical and entertaining places in Turkey.

This year the event will take place between 29th May - 3th June 2005. It will start in Ankara and finish in Antalya. Accommodation, nutrition, transportation and all other expenses for the programme will be

refunded by LOSEV. During the week, our guest children will be accompanied by a hematologist and a nurse with a fully equipped ambulance. Required health checks and treatment will be provided by LOSANTE - our Hospital for Children with Leukemia.

Aims of IV. (International) Week for Children with Leukemia

Throughout the IV. (International) Week for Children with Leukemia we aim to:

- Increase the world's public awareness on the rapidly growing childhood leukemia cancer incidences
- Provide a platform to enhance the solidarity amongst all children with leukemia and to establish a fusion between cultures
- Put common problems that leukemic children and their families face on the world agenda
- Bring about permanent solutions to the problems our children with leukemia and their families experience
- Stress that leukemia is a curable but an exhausting disease
- Emphasize that drug therapy is not sufficient to overcome this disease; nourishment, hygiene and especially psychological support are as important as the drugs for succeeding

- State that more emphasis should be given to educational studies to avoid leukemia, our children should be spared environmental risk factors and doctors and other medical staff should always be supported to achieve these goals
- To lay the groundwork for the recognition of IWCL by countries all around the world and for making it available for the event to be hosted every year in another country

With the increasing participation of children from all around the world we are getting closer to our foremost important goal which is:

- TO INCREASE THE TREATMENT SUCCESS TO 100% AND TO GIVE OUR CHILDREN A HEALTHY AND PROSPEROUS FUTURE.

One of the most important aims of the week is to develop the cooperation between such organizations and make it available for us to create common solutions and policies which also fall within the objectives of the ICCCPO "to improve access to the best possible treatment and care for children with cancer everywhere in the world". We have a dream, a world without leukemia. This dream can only be realized through the co-operation of people and institutions from all around the world.

The documents and required forms are sent through the Turkish Diplomatic Missions to organizations for children with leukemia almost all over the world.



Information about organizations, requirements and application forms can be also obtained from our web site (www.losev.org.tr). All institutions may also contact us directly (international@losev.org.tr)

*Pediatric Hematologist
Dr. Ustun EZER
Chairman of the Executive Board*

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Dear Editorial Staff:

I would like to say a few words about the role of my participation in ICCCPO-conferences.

Since I am engaged in the activities dedicated to the problems of cancer children and their families, I listened to all lectures of ICCCPO-conferences with great interest. I had the honour and pleasure to attend three conferences. I pay extra attention to and have a special interest in the work and experiences of my colleagues who work for children with cancer all over the world. It's a good chance for me to meet and talk to them, not only obtaining important information about

their work, but also having the chance to hear various opinions and different attitudes regarding very specific projects for children with cancer and their families. All this encourages me and my colleagues in

the Ukraine and gives us new strength in our work.

It's a great honour for our Charitable Fund "Viden" to be an associate member of ICCCPO – the best confederation in the world which dedicates its activities to the struggle against paediatric cancer. We spread the knowledge and experience of ICCCPO and support all its initiatives in the Ukraine!

I want to express my special gratitude to all my ICCCPO colleagues and to our reliable partner, the Austrian Kinder-Krebs-Hilfe which makes my participation in the conferences possible and shows great understanding and support of Ukrainian patients and their families.

*Yours faithfully,
Svetlana Shut
Ukraine, Sumy region*



Open Letter to my Child's Doctor

Dear doctor,

I have a lot of things to tell you. I will make the effort to bring you into line with me so that we can both see through my eyes, the eyes of a parent, what it is that a parent expects from her child's physician. It is an attempt to establish cooperation and mutual respect between the physician and the parent, and to achieve the optimum result.

Many thoughts ran through my mind before I wrote this letter:

- Experiences, not only my personal ones, but also those of so many other parents.
- The necessity for good cooperation amongst us and the possibility of rendering it more efficient.
- Understanding, and the way that both parents and doctors can express it
- Truth, and how much can be expressed without creating any problems
- Opposite viewpoints and to what extent they overlap
- Human weaknesses and to what extent these can be surpassed.
- First of all, allow me to say a few words about us, the parents, who constitute the Parents' Associations all over the world, who we are and what our wishes and expectations are.

We are not anybody special or particular. We are ordinary people, facing everyday life and, until yesterday, we considered the presence of our children an undisputable fact.

And suddenly, clouds darken our blue skies. As simply as that. One day; one morning. The whole of our life and everything that we were trying to build and establish up to that moment is turned upside down within a single moment, without warning, without reason or any cause. We are suddenly confronted with an unbelievable fact: our child suffers from cancer !

Resentment is succeeded by anger and anger by scruples - a chain of sentiments to be endured by all parents under these circumstances. For how long will resentment, anger and scruples prevail? This depends on many factors. These factors are ourselves, our character and age, our education and culture, our surroundings, our friends and above all, our doctors. But we must endure, and so we do.

All of a sudden, from one moment to the next, irrespective of the level of education of any of us, we have to learn what, in fact, cancer means when a child is affected, which medical institutions cope with it, the therapeutic options that exist in Greece and abroad, of what chemotherapy consists and what the side effects

are, what it means for the patient to have low white blood cells and blood platelets, what the therapy protocols mean and a large number of other things.

In contrast to you, dear doctor, who chose and prepared yourself to become a doctor and the physician of my child, I, personally, was neither asked nor have I ever chosen or ever intended to step into your office for consultation under these circumstances.

The endeavors intended for our children

First and foremost, we are concerned to have doctors with a sound professional training and specialization in this field to look after our children, because, prior to securing quality of life, we are concerned with life itself for our children. We request that the State establish measures for a continuous post-graduate training for doctors, but also of an evaluation of their capability. We also request specialization studies in the field of oncology, the registration of cancer cases in children, the treatment protocols, the final outcome etc.

The life and death of our child is our main concern and obligation, and, therefore, we believe that it lies within our responsibilities and rights to address any action which concerns and is directed at the child's life, to whatever authority and in whatever direction.

Prompt diagnosis means prevention of cancer

Allow me to refer first of all to the general pediatric practitioner, as I consider him to be the first and basic factor which may lead to the final cure of our children, because it is from him that we expect a prompt diagnosis, or at least the prompt referral to hospital.

At this point, I wish to mention my personal experience, because I still believe that if my daughter's pediatrician had listened attentively and had looked into my concerns and investigated the matter, if he had been properly informed, if some public factor had obliged him to present himself in hospitals now and then, if he had come across a similar case in his career, then possibly the diagnosis might have been made in due time and maybe, Alexandra would be here with us today. Symptoms were more than obvious (as was ascertained afterwards) and yet he still did not understand precisely what the matter was and, what is more, he stopped us from going to hospital.

Mention of this specific case is not being made just to reopen old wounds.

I wish that these cases constituted the minority, but – alas – it is not so. Children's lives are lost because their pediatrician is not in a position to understand the cause promptly and because he refuses to listen to the anxieties of the parents, rejecting them before examining them.

The mother's instinct should be followed. It will lead you the correct way. Listen attentively to what she has to say. Changes in the child's behavior lead the mothers to you and you, in turn, should look into the matter and weigh up the anxieties.

The whole responsibility for a prompt diagnosis lies with the general pediatric practitioner. The pediatrician must have the required knowledge and experience in order to gain time: time to start treatment promptly and consequently to have the best possible result. We have been told that pediatricians, while practicing for their special areas, visit and practice in all the departments of children's hospitals, except in the oncology wards, because there is no such special area. But, since there is no such special area, how come there is a department in hospitals? Since, then, there is a department and children with neoplasia are hospitalized there, that means that a pediatrician will not have the opportunity to encounter such a sick child and, therefore, he will not have dealt with a child suffering from cancer during the whole period of his practice, the only chance of his coming across a case of cancer is in the hospital's out-patient department, where, however, the special oncologist pediatrician will be called. The result, therefore, is a child with cancer visiting his practice and the doctor, not having acquired previous pertinent experience and knowledge, often cannot make a prompt diagnosis.

Pediatric Oncologist

My dear doctor, as of today, the diagnosis concerning my child having been made, you will have a permanent place in my life and in my thoughts and your name will often be referred to in my home. We have become acquainted under circumstances so very pressing and unpleasant. However, we are meant to proceed to a relationship based on a common endeavor and cause. My wish is to proceed with all our strength, each of us from a different position and with a different role, in order to succeed in our common purpose – the best medical care possible and final cure, the assurance of quality of life during the time of therapy

and the appropriate integration of the child in its social surroundings.

Before proceeding to an analysis of all the things I expect from you, I will ask for your understanding and I will try to make you see why I ask for so many things. I have huge expectations from you, because your job, your profession, deals with the life and death of my child. There is no way back, there is no room for amendments, asking to be excused because of an excessive workload cannot be accepted, mentioning that not enough attention has been given or it has escaped the doctor's notice and therefore, a mistake has been made, cannot be accepted. Our children do not come back. Children are not accounting books to be corrected later on, they are not a lesson with mistakes in the classroom, which can be corrected the following day, they are not a wrong purchase, which can be revoked.

My wishes concerning you



As long as my child is under your care, I am very much interested in and concerned for your well-being in general, both as a doctor and a person. It really is my sincerest wish that you be happy at home and that you enjoy complete personal and family peace and stability. In this way, you will be able to develop all your capabilities and sensitiveness and dedicate all the attention needed to the field of your professional career, the successful course of which is directly connected with the biological and psychological healing of my child and its natural integration in the social surroundings.

If need be, you may bring home – your home – my "case" but not my "problem". Every time a child is lost, I really wish that you will not suffer, but that you will increase your efforts to improve your knowledge to acquire better results. So that your mind may remain open and clear, you must protect yourself from the pressure of your work and failures.

Meeting for the first time

When we first meet, do not be abrupt, do not expect me to easily accept everything you have to say to me. You should not put me off with an austere, cold and brusque briefing, leaving out any hope. At that moment, you are the fellow person, perhaps you are a parent, please be polite and patient, please respect the tempest that has suddenly befallen my life. From now on we will, unfortunately, meet frequently and daily, so

you can tell me what is required. Please, allow time for me to weigh up and recover my strength, to find weapons and defences, to stay upright at my child's side.

You yourself may have seen many parents in this same situation and the briefing of new parents may have become a routine matter for you, but, please, do not forget that it is the first day for me, the first briefing for me and that it concerns the life and the death of my child.

Allow me room to stand, because suddenly my own life acquires a particular value, since now I am obliged to live, for I have to offer my assistance to my child.

Dear doctor, please consider that until yesterday I did not know you, I did not even know what a neoplastic disease meant for children. Until yesterday I did not even know that cancer also affects children.

My mind perceived the "abominable" disease and the unavoidable and awful end of life associated with it. Mostly through television channels and newspapers, people learn to mistrust public hospitals. At the time I was being informed, as a first step and for the first time, my mind went back to everything that I ever had come across concerning negligence and errors on the part of doctors, delays, camp beds filling the corridors, miracles happening abroad and many other things, all of which make me feel insecure and mistrustful towards you and the public hospitals represented by you.

I find myself in a whirlwind, which, if it does not calm down, will not allow me to understand the changes it has brought to my life and let me concentrate and tidy up the ruins left behind.

What I expect from you

My wish is first and foremost that you may set aside any selfish sentiments and that in a spirit of goodwill, you may cooperate and unite forces with your colleagues and attain the best possible results for my child. My wish is that your colleagues be your cooperators and not your rivals. I wish that you may all hold frequent conferences concerning the therapy protocols and their outcomes. If your views do not coincide, you should, please, consult other doctors in Greece or abroad and check your doubts and fears. Please send the specialized centres a few tests which may prompt queries, and seek a second opinion.

Do on your own initiative whatever the State does not compel you to do. Always be in a state of continuous awareness, revise your knowledge, update the therapy methods, try to steadily improve the nursing conditions, be permanently at the centre of medical development in your field.

Accept the possibility of your being mistaken, admit your possible error in time and don't be selfish, but take corrective action immediately.

Please help me with your behavior to be acquainted with you, to know you, to evaluate your personality and feel secure leaving my child's destiny in your hands. Please, be accessible, friendly and modest so that I may feel at ease and ask you again and again about something I did not understand or do not want to understand.

My wish is to be treated equally. Whoever I happen to be, a minister or a worker, I am entitled to and wish my child to have equal opportunities to recover and have the same attention.

Please be kind enough to understand my insecurities, to accept my doubts and not be annoyed when I want to have a second opinion about my child's condition and prospects. If I have been told of a colleague in your field in Greece or abroad, who I think can be of help, do not consider it humiliating - let me ask for his opinion. If I consider that it is to my child's advantage to be taken care of in another hospital, be it either the one next door or in another country, please hand me my child's file and let me go. I can use my discretion to choose my child's doctor and I have the right to do so. If, somewhere, there is a better prospect, an additional hope, you, dear doctor, ought to inform me and assist me in chasing it up. It is fundamental for me, extremely fundamental, to rest assured that I did everything possible for the sake of my child.

Please, think thoroughly before talking to me and be sure about what you have to say. Tell me about your "ascertainments". Your fears and anxieties should be investigated, discussed with your own self and with your cooperators.

Please, it is my wish that I should be listened to attentively. I want to trust my parent's intuition and to have my remarks with regard to my child taken seriously, because they may lead you to useful conclusions for the course of the disease.

Please, talk to me patiently, plainly and clearly, in accordance with my perception and capabilities. Each one of us parents is a unique individual with different capabilities, intellect and education.

Since you are a member of a team, my wish is that you operate as a team and that you discuss your doubts within the team and not with me. My wish is to hear a justified view from you, the result of cooperation amongst you all.

Your professional training is of most importance to me, but this alone is not enough for me. My wish is that, through your friendly and pleasant behavior and your assurances, you may be able to convince the child itself to feel secure and to accept the fact that all the painful treatment and medical tests are temporary and should be carried out for its own good.

Please, pay attention to the child during the final stage, and the child's family. Continue to strive till the last moment. My wish is that you may remember that everything you say is of particular importance both for the parent and the child listening to you. Before starting to talk, think carefully about what you going to say. Pressure on the family is terrific and balances are particularly fragile.

Please, keep in touch with the children who have been healed, be interested in the course of their health, discuss with them their anxieties and fears and answer their questions.

Please do understand that you are a professional, caring for health and I am a parent striving for my child. We are engaged in the same fight but in different roles. My wish is that you respect the autonomy of the Parents' Associations, that you may always be in touch, cooperating with them, for the development of a real coalition to the advantage of all children.

Epilogue

My family and myself have been deprived of the presence of our Alexandra for 18 years. Circumstances have obliged us to live these 18 years without her. Now, after such a long time, we have realized that even those six years she was with us were enough to fill us with experiences and memories for a whole life. The two years we fought to keep her with us, were transformed into the most significant part of our life. For two years, we travelled from hope to disappointment and from heaven to earth. We filled our hands and hearts, we offered our worship and enriched our life with sentiments never before felt and utterly moving. We were given the opportunity to stay by the side of this child, who, like all the other children of "Floga" developed unbelievable powers, surpassing human nature and teaching all of us who happened to be next to her, what is the meaning of love, strength, self-respect, decency and courage.

A glimpse of life, so brief, yet so intense, a glimpse so tiny, yet so sturdy. A glimpse of an existence never having faltered in our home, because the doors of our souls have been kept wide open, as our embracing arms offered hospitality, with room for all those children fighting their battle, the same battle with the same passion and the same decency.

Dear Doctor,

At this precise period of our life, and regardless of whether we were able to keep our children with us or not, your presence is of foremost significance and most decisive. In all the years to come, you will have a place in our mind and in our everyday life, having found yourself involved in our child's journey and having been related to our child's destiny.

Let these memories be good !

Let us be proud of the presence of our child in our lives and let us remember dearly your passage in our child's life!

Let us be allowed to mourn the passing away of our child, without scruples and doubts for our decisions. Extend to our soul peace and assurance and you will have our love and respect.

It depends on you.

*Maria Trifonidis
President of Floga*



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

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Urgent request from the Secretariat

We kindly ask our members to inform us of any change of address, e-mail, website, telephone and fax. It is hard to keep in touch when our contact list is not updated, and staying in touch is what ICCCPo is all about.

Could you also inform us of new parent organisations in your region? They may be interested in joining ICCCPo and we could send them the necessary information and documents.

Thank you for your help!
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