

A Note From the Chair



If your organisation wishes to host the Executive Committee for the mid year meeting in 2003, please contact Marianne Naafs or Simon Lala (EC).

The programme for the ICCCP Conference in September this year is almost finalized. It looks very promising and ensures a successful meeting. We anticipate to meet many of you at the conference and

In March the Executive Committee met for its mid-year meeting in the scenery of the beautiful castle of Echouboulains and its gardens (France). We had the chance to meet with the French parent groups who had a national meeting at the same time and to introduce ICCCP to them. It was a productive meeting in many ways. For a couple of days we lived in a simple house where we shared rooms and prepared our own meals, and in those days we got to know each other better and our solidarity grew stronger. We were there to serve a common case: to improve treatment and care for our children.



We deeply thank the people of L'Envol for the excellent arrangements and their warm welcome.

Annual General Assembly in Porto (Portugal). There are several joint sessions with SIOP. Details about the programme and the first international survivors' programme are elsewhere in this newsletter and on our website.

By the way, the ICCCP-website deserves a regular visit! www.icccpo.org

Marianne Naafs-Wilstra
Chairwoman

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Editorial Staff:

Gerlind Bode

Pia Bonini

Marianne Naafs-

Wilstra

Address of Secretariat:

International
Confederation of
Childhood Cancer
Parent Organizations,
c/o VOKK,
Schouwstede 2d
3431 JB Nieuwegein, NL
tel: +31 (30) 2422944
fax: +31 (30) 2422945

Bank Account:

Bank of Nova Scotia,
Concord, ON,
No. 830 220 024 813

US \$ Account:

CenE Bankiers, Utrecht
No. 16128

€ Account:

CenE Bankiers, Utrecht
No. 69 92 11 875

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

International Childhood Cancer Day in Bangladesh



CLASS Executive Committee members seen visiting Leukaemia Block at CMCH on December 13, 2001. On the right is Dr. Chowdhury B. Mahmood Head of Child Health Department, CMCH

On January 15, 2002 - as declared by ICCCP - for the first time the International Childhood Cancer Day was performed in our country. Our program in Chittagong and Dhaka included a colorful rally brought out in the morning on the occasion by CLASS (in Dhaka by our Dhaka unit) and participated by hundreds of school students, boys and girls, enthusiasts. The Chittagong rally was led by the Mayor of Chittagong City Corporation Alhaj A. B. M. Mohiuddin Chowdhury. The rally, after parading main city streets, terminated at Press Club premises where the Mayor addressed the participants and others who gathered to work for fighting the menace of cancer. The participants wore T-shirts and headgears on which the logo and name of the organization, International Childhood Cancer Day were beautifully printed to create public awareness about childhood cancer.

Leukaemia Treatment Facilities Alarming Inadequate

Specialists stress need for paediatric haematology unit in every hospital of the country

Expert physicians participating in the first ever international seminar on Paediatric Haematology and Oncology in Chittagong (Bangladesh) expressed deep concern that facilities existing in the country for treatment of this child-killer disease were very inadequate. They stressed the need for introducing a Paediatric Haematology unit in every medical university hospital of the country to meet the needs.

Participating experts claimed that the country had made a good headway in controlling diarrhoea and conteagous diseases and thus reducing the

Leaflets were also distributed to attract public attention. A big-size banner was carried by participants in front of the rally to signify the Childhood Cancer Day.

In the afternoon, a seminar was arranged at Zia Auditorium chaired by Shafiqul Alam Khan, President of the Rotary Club of Islamabad, Chittagong. The seminar styled as Childhood Cancer Care, was addressed, among others by Rotary Dist Governor (Bangladesh R.I. Dist 3280) Engr. Abdul Ahad, Mr. Farid Ahmed Chowdhury,



A view of 3rd Annual General meeting of CLASS held on December 13, 2001 presided over by Chairman of the organization Osman Gani Mansur

President, Chittagong Chamber of Commerce & Industry, Mr. Golam Rabbani, Director of the Chittagong unit of the Bangladesh Red Crescent Society, Prof. Dr. S. M. Fazlul Haq, Chairman Maa-O-Shishu Hospital, Prof. Fariduddin Ahmed of the Child Health Department, Chittagong Medical College Hospital and CLASS Chairman Osman Gani Mansur.

death rate significantly, while blood cancer an Thalassaemia are a grave threat to our children. It also came up for discussion in the seminar that advanced countries have achieved tremendous success in treating patients with cancer and thus bringing the recovery rate up to seventy-five percent. Whereas our success in this filed is very meagre and frustrating. Evidently, such a situation can be attributed to lack of expert manpower, lack of supply and the high prices for the necessary medicine besides failure of insolvent families to start treatment in time and afford to continue that for a prolonged period as required.

All the speakers observed that development of expert manpower, setting up of standardized laboratory, creating public awareness and government and nongovernmental patronizing were necessary to overcome the present alarming situation in respect to cancer treatment.

Osman Gani Mansur, chairman of CLASS (parent-initiative Bangladesh)

All the speakers unanimous observed that we needed to do a lot of things to reach a minimum level of cancer-treatment. They pointed out extreme poverty, lack of worthwhile initiative from the Government, very low level of awareness among the people, non-availability and high cost of medicine and inadequate publicity as major causes of the present alarming cancer-situation in the country. They said that as a remedial measure, side by side with Government efforts, voluntary and charitable organizations have to make coordinated efforts to bring the situation to a take-off

stage prior to embarking upon more specialized plans in the field. The meeting also eulogized Children Leukaemia Assistance & Support Services (CLASS) for its pioneering role in initiating treatment of cancer-stricken children coming from very poor section of our society.

All the events in the seminar and rally, were given extraordinary coverage by press and electronic media. Some foreign TV Channels also covered the program.

Osman Gani Mansur
Chairman of CLASS, Bangladesh

Conventional vs. unconventional treatment

Excerpts from a lecture held at the SIOP/ICCCPO- Conference in Brisbane (Oct. 2001)

The term "Conventional Therapy" is applied to any form of treatment that is widely practiced and shown to be of value in reports published in worthy scientific journals. In pediatric oncology (particularly in the treatment of leukemias) we can state that the excellent treatment results are based on 30 years of clinical research with controlled and randomized trials.

"Unconventional Therapy" is any approach to treatment beyond the definition of conventional therapy. It includes:

Alternative medicine used "in place of" a conventional treatment and **Complementary medicine** used "in conjunction with" conventional treatment.

Examples of unconventional therapy (with respect to the treatment of children with cancer):

- Acupuncture
- Biofeedback
- Dietary supplements
- Homeopathy
- Hypnosis
- Massage
- Imaging
- Essential Oils
- Vitamin Therapy
- Chiropractic
- Aromatherapy
- Spiritual Healing
- Relaxation and Meditation

A study by Karadeniz et al. about the use of complementary therapy in children with cancer shows that 50,6% of the 84 patients asked used at least one complementary component such as dietary supplements or faith healing. Only 9,3% of these families discussed the use of any complementary medicine with their physicians.

Only in rare cases alternative therapy is used, meaning, the therapy based on scientific knowledge is completely denied.

In adulthood, the incidence of using "other" medications is much higher – between 45 and 83% (Journal of Clinical Oncology, 1998).

The answers to the question "Why is complementary therapy used so commonly?" were collected by Burstein et al (JCO, 2000):

Patients reported:

- It would make them feel better
- They would have a wider control over the decision making program
- It could reduce pain, anxieties or emotional distress
- It would improve the quality of life, relief from side effects of the conventional therapy and boost the immune system.
- But no one believed to treat the actual malignancy with these measures.

Patients (and parents) should be very cautious about applying any other than conventional therapy when:

- The treatment is a "secret" that only specific individuals can provide
- The treatment promises a cure for almost all cancers or medical conditions
- The promoters claim to be persecuted by the medical establishment
- The promoters attack the medical community

(Metz, J. Medical and Ped. Oncol., 2000, vol. 34)

However, as much as complementary medicines are considered to be "harmless" one has to be aware that a number of regimens are not. On the contrary they can induce complications and many cause side effects. For example Aristolochia fangchi is a mixture of Chinese herbs (which is some times also prescribed by weight loss clinics) is known to cause progressive renal failure and consecutively bladder cancer.

Examples of herbal toxicity:

Aristolochia fangchi	bladder cancer
Borrago officinalis	veno-occlusive disease
Tussilago farfara	liver necrosis
Eucalyptus globulus	ataxia
Camphora	convulsions
Gingseng	hypertension

(Berman et al, Lancet 200, Davanzo et al, Riv. Ital. Ped., 2000)

- Do not refuse the use of complementary therapies but listen carefully to the patient
- Accept what is useful for the patient (even if only from a psychological point of view)
- Avoid treatment with known adverse or toxic effects
- Value possible interactions between herbs and drugs (Brustein et al, J. of Clin. Oncol. 2000)

Precautious Advice:

While physicians do not include alternative therapies in front line protocols (due to the lack of documented efficacy) they should carefully consider requests by parents/patients of using "other" treatments in palliative care. In some cases it might have a positive psychological impact which might improve the quality of life and the compliance in this stage.

Thus I would like to recommend to my colleagues:

- Ask the patient about the use of complementary therapy

We have to open the access to complementary therapies by starting the dialogue between physicians and patients and by promoting serious research in this field. Every child has the right to receive the best possible treatment. Every parent has the duty to guarantee the best possible treatment to the child. Different from adulthood, the society intervenes to guarantee the rights of children. So, alternative medicine should not exist in pediatric oncology.

Dr. Momcilo Jancovic, Childrens Hospital, University of Milano, Monza, Italy

Medical Information: Retinoblastoma

Retinoblastoma is a malignant tumor of childhood that arises in the retina of the eye. The majority of cases are diagnosed before the age of five years. The incidence of retinoblastoma is higher in developing countries than in Europe and the United States, where the age standardized annual incidence rate is about 4 cases per million. In some developing countries, the incidence rates per million may be two to six times higher (Figure 1) or even more, since very little information is available from rural areas, where retinoblastoma appears to be particularly common. About 20 to 30% of patients have bilateral disease. The disease may occur sporadically or it may be inherited. It is characterized by a rapid growth rate. When the disease is detected at early stages and confined to the eye, children have a good prognosis and the anticipated five-year disease-free survival rate (DFS) is 90% or greater. However, in children with disease that extends beyond the eye, particularly to distant parts of the body, the five-year DFS is poor, less than 10%. The percentage of children with extraocular disease (outside the eye) at diagnosis is much higher in developing countries (approximately 35 to 50%).

The two most common early symptoms observed in children are leucocoria (cat's eye reflex) and strabismus (squint). Other signs of the disease include redness of the eye, fixed pupil, or other more subtle changes. When the disease is more advanced, patients may experience swelling of the tissues around the eye, proptosis (protruding eye), or sunken eye. Change in or loss of vision may also occur, but this is difficult to assess in very young

children. In addition to a detailed ophthalmologic (eye) examination performed while the patient is under anesthesia, special x-rays and ultrasound evaluations are used to establish the diagnosis.

Ophthalmologists, and radiation oncologists are all essential members of the multi-disciplinary team needed to effectively treat patients with retinoblastoma. The goal of treatment is cure and preservation of sight. The therapeutic approach is dependent upon factors such as whether the disease is unilateral or bilateral, the potential for vision, the size, location and number of lesions, and whether the disease has spread beyond the eye. Availability of treatment modalities as well as the expertise of a particular center in the management of patients with retinoblastoma are also important considerations. For small tumors within the eye, treatment consists of external beam radiation, photocoagulation (laser), or cryotherapy (precise freezing). When tumors are large or if there is little expectation that vision can be preserved, the eye is removed. The use of systemic chemotherapy to reduce tumor volume prior to a physical treatment modality to permit preservation of vision is currently under investigation in Europe, the USA, and many developing countries. The most common chemotherapy drugs used for chemoreduction are carboplatin, vincristine, and etoposide. In patients with extraocular disease, particularly those with spread to the central nervous system or bone marrow, chemotherapy is the primary component of treatment.

Melissa Adde
 (INCTR-Newsletter „NETWORK“, Volume 1, Number 3, Winter 2000)
www.inctr.org

Some guidelines when considering Complementary Medicine

(National Center for Complementary and Alternative Medicine - NCCAM)

Approaching Complementary and Alternative Therapies:

The decision to use complementary and alternative treatments is an important one. The following are topics to consider before selecting an alternative therapy: the safety and effectiveness of the therapy or treatment, the expertise and qualifications of the health care practitioner, and the quality of the service delivery. These topics should be considered when selecting any practitioner or therapy.

Assess the Safety and Effectiveness of the Therapy

Generally, safety means that the benefits outweigh the risks of a treatment or therapy. A safe product or practice is one that does no harm when used under defined conditions and as intended.

Effectiveness is the likelihood of benefit from a practice, treatment, or technology applied under typical conditions by the average practitioner for the typical patient.

Examine the Practitioner's Expertise

Health consumers may want to take a close look into the background, qualifications, and competence of any potential health care practitioner, whether a physician or a practitioner of alternative and complementary health care.

Consider the Service Delivery

The quality of the service delivery, or how the treatment or therapy is given and under what conditions, is an important issue. However, quality of service is not necessarily related to the effectiveness or safety of a treatment or practice.

Visit the practitioner's office, clinic, or hospital. Ask the practitioner how many patients he or she typically sees in a day or week, and how much

time the practitioner spends with the patient. Look at the conditions of the office or clinic.

Many issues surround quality of service delivery, and each one individually does not provide conclusive and complete information. For example, are the costs of the service excessive for what is delivered? Can the service be obtained only in one place, requiring travel to that place? These issues may serve as warning signs of poor service.

Consider the Costs

Costs are an important factor to consider as many complementary and alternative treatments are not currently reimbursed by health insurance. Many patients pay directly for these services. Ask your practitioner and your health insurer which treatments or therapies are reimbursable.

Find out what several practitioners charge for the same treatment to better assess the appropriateness of costs. Regulatory agencies and professional associations also may provide cost information.

Consult Your Healthcare Provider

Most importantly, discuss all issues concerning treatments and therapies with your health care provider, whether a physician or practitioner of CAM. Competent health care management requires knowledge of both conventional and alternative therapies for the practitioner to have a complete picture of your treatment plan.

More Information: National Center for Complementary and Alternative Medicine Information
NCCAM Clearinghouse, USA
Toll-free within the USA: 1-888-644-6226
International: +1(301)-519-3153
TTY (for deaf or hard-of-hearing callers): 1-866-464-3615
E-mail: info@nccam.nih.gov
Web site: nccam.nih.gov

What the future might bring...

Once every year a major event in cancer research takes place somewhere in the United States: the annual meeting of the American Association for Cancer Research (AACR). Some 15,000 basic, translational and clinical researchers from all over the world come together to communicate the latest results in their field of work. Reading this some people must think that it would be a great opportunity to be able to attend an event like this: it was!! In some extraordinary way the AACR got the address of our organization (VOKK) and invited us to propose someone's participation during their 4th Scientist <-> Survivor program. After applying I got invited to come. Being a 19-year-old childhood brain tumor survivor I was by

far the youngest, but since I'm a second year medical student I was one of survivors that was able to understand most about the work of cancer researchers.

The purpose of this article is to describe some the vast array of research that is being done to accelerate progress in the fight against cancer. It will be hard though to go into much detail: I'd much rather give you an overview of what might be expected during the next five to ten years.

I think by now many people have heard about the human genome project: a worldwide project to find the sequence of all our genes: our full genome was evaluated by hundreds of laboratories throughout

the world. Each of those has been trying to sequence their part of the genome that they had chosen for study (finding the genetic alphabet). These researchers have now almost reached the point at which our whole genome is 'known' (about 95 %, the remaining 5 % will be hard to find out). This gives us the possibility to search for differences in the genetic code between normal (non-cancerous) body cells and cancer cells: specifically, those mutations that cause these cells to grow abnormally fast. Knowledge about the genes that are involved in changing a normal cell to a cancer cell opens the possibility to invent drugs that inhibit or antagonize the gene's abnormal protein. It has hope that this form of drug selection would allow the drugs of the future to act specifically on cancer cells (normal body cells don't have these proteins and aren't affected by the drugs), a process that's called targeted therapy.

In some cases this theory has proven successful already: a compound called Gleevec has shown to be very effective in the treatment of Chronic Myelogenous Leukemia (CML) which carries a mutation on chromosome 9 and 22 (called the Philadelphia chromosome or the Bcr/ Abl translocation). The drug is now being evaluated in clinical trials on various other diseases that carry the similar mutation. This process may take months or more likely years before the drug is accepted for treatment of larger groups. Many pharmaceutical companies have started developing drugs that attack newly defined molecular targets, hoping to contribute to the treatment of cancerous tumors while reducing the serious side effects that have characterized most forms of cancer treatment in the past.

But there are other things going on too: for some years now, researchers have been experimenting with anti-angiogenic drugs – agents that interfere with the development of new blood vessels within a tumor that allow it to grow. Our knowledge about tumors showed us that even potential malignant tumors would not grow any bigger than 0,2 mm if there wasn't enough blood supply (nutrients, oxygen). If there was however, these tumors would expand rapidly and obtain the ability to spread to other sites too (metastasize). The idea suggested here was to prevent blood vessels from forming by inhibiting their growth (anti-angiogenesis). In the beginning researchers hoped to even be able to shrink larger tumors, but nowadays the general view is that these drugs can potentially prevent smaller tumors and distant metastases from growing larger but can't make them disappear. The other problem they are still fighting with in this regard is the variety of ways that tumors seem to be able to recruit blood vessels: the more pathways being used, the harder it is to prevent angiogenesis. In brief, there is still much research to be done, but this field seems less promising than it was initially thought to be.

Instead of antagonizing or inhibiting the proteins produced by the cancer cell you could also try to repair the genes that are damaged: this process is often called gene therapy. The concept is to insert the right (essential) gene into the tumor cells (often one of the DNA-repair genes) so that the loss of this gene is made up for. The problems have always been to find this essential gene and get it delivered to the cancerous cell. Once delivered it has to be expressed too. Thanks to the many people searching for ways to do this, there are now some promising results by using retro- and other classes of viruses that can carry a gene into a cell. These viruses may also deliver their own genome into the host cell. By deleting the gene that is capable of causing viral illness from the viral genome, the virus won't be able to do any harm but will function as a transport mechanism. It still is hard to get the virus delivered to the tumor and make it infect the tumor cells, but once the gene has been delivered it has shown to have a potential of contributing to the control of disease. One of the problems facing this field of investigation is the recognition that for a normal cell to transform in a cancer, several different mutations must occur. Will the substitution of one gene be enough to change the behavior of a cell? More likely several changes will be required.

The final new method I wanted to discuss is immunotherapy. Wouldn't it be nice if we could teach our body to recognize the cancerous cells, because they are different, and kill them by itself? Our body has a couple of potentially killing cells such as lymphocytes and other cells of the immune system. If they could recognize the cancer cells as being different and invoke mechanisms that would specifically get rid of these cells based, on the presence of specific recognizing proteins on their cell surface, a major advance in cancer treatment would be achieved. The goals for the coming years is to find the best ways to teach these cells to differentiate between healthy and unhealthy cells, but the work already done looks promising.

Surveying all the efforts that are taken to tackle this problem, I expect that the next five to ten years might provide us with some significant advances in cancer therapy. It might even include a more specific way of preventing the development of cancer in families who are recognized to be at high risk. There is one thing we should try and keep in mind though: to make it possible for the scientists working in this field to make these steps forward, they'll need time and resources. So while most of us must patiently wait for what future might bring, we could try and support the efforts of the international scientific community in its task to find ways to prevent, diagnose and treat cancer.

Eva Coenen, The Netherlands
Survivor and member of the International Survivors Network

Family policy and basic child/parent needs

Family policy refers to a conscious, planned and targeted intervention of public authorities in the structure and the functioning of families. More precisely, it refers to the objectives and the measures taken by governmental bodies in order to achieve family well-being. It represents the point of intersection between private and public sphere.

To provide care and support to the child with cancer and his family requires that parent organizations take into account some preliminary observations:

- The treatment period is considerably long
- There is a lot of anxiety and fears related to an eventual relapse during the immediate post-treatment period
- The treatment is expensive
- Healing proportion is generally between 70% and 80% of the treated children
- Cancer has an impact, not only upon the child, but also on his family
- Usually, women take the heaviest part in providing care to the ill child
- The child's disease may worsen pre-existing family problems
- Most insurance systems deal with the "normal family", consisting of both parents and the unmarried children. Nevertheless, social change leads to the emergence of new family types that should be taken into consideration while trying to outline the family policy (single parent family, recomposed family, family of adoption, polygamous family, nuclear/extended family, etc.).

Some of our basic needs

While in the developed countries the state is taking care of many crucial needs of the families with cancer sick children, in most developing countries, state services refer only to a small proportion of the families. In addition to many other problems, they are still suffering from dramatic shortages in drugs, housing, transport, social and psychological support. To outline an appropriate family policy, the following needs have to be satisfied:

a) Needs related to the parents and the family:

To take into consideration, not only the individual (the ill child), but also the family as a whole, including the grand-parents

To provide a care allowance for the parent, or the family member who is most involved in taking care of the ill child

To provide specific support to the parent who himself may have a disease, disability, or is unemployed or in a situation of extreme need

To compensate the families for bearing particular charges such as taking care of an ill child or disabled

survivor, or for expenses on transportation, housing, drugs, etc.

To adapt financial assistance and social support to the child's family which could be characterized by extreme poverty, isolation or parent's unemployment. One of its members may also be disabled or retired.

To provide support to pregnant mothers of children with cancer, and to those who are taking care of the new-born babies;

To help coping with the consequences of a divorce that could otherwise lead to child abandonment before the end of the treatment;

To approach social security as a welfare mix where different sources of support are to be combined

b) Needs related to the children:

To dedicate special attention to the ill child whose parent is alcohol or drug dependant, dealer, aggressive, prostitute, beggar, etc., and simultaneously, cooperate with other associations and public institutions to generate the best possible family atmosphere for the ill child;

To take responsibility for children who were abandoned during the treatment until they are either taken back by their families or are adopted

To allow children in process of treatment to obtain authorizations of absence from school without losing the right to take the exams.

To alleviate the effects of the disease on the siblings of the child and other members living in the same household

To extend insurance coverage for the families who are lacking it, at least during the treatment period

c) General family needs:

Prevent that any family policy actions could be perceived as "intrusion" into the private and intimate family sphere

Prepare a "parents' guide" that informs them about helpful health services and administrations, as well as financial obligations and possible steps to undertake.

Promote training strategies for all the professionals who are involved in providing social and psychological support to the child and his family
Reinforce all voluntary networks in support of the ill child and his family

Renew all kinds of support in case of relapse.

The conciliation between work and child care

To allow parents a better conciliation between the childcare requirements and their professional

and domestic commitments, the following aims have to be pursued and applied whenever they seem suitable and desirable from the family point of view:

- Work hours of the father or the mother should be easily reduced during the time of treatment
- Ease the possibility to take leave of absence during this time. This should also apply to men in order to increase male involvement in providing care to the child
- To take into consideration the child's treatment requirements in any job shift
- Compensation for health care expenses for the ill child at home as well as compensation for the costs for the recruitment of domestic help

The importance and authority of the family

Public, private and civic institutions should not replace the family in its fundamental role of insuring care and services to the ill child. Priority should rather be given to the strengthening of its autonomy and self-reliance and the reduction of its dependency towards external services. To implement this goal, the following measures have to be taken:

- Strengthening of family autonomy and self-reliance whenever it is possible
- Improvement of communication between health care institutions and families
- Provision of financial, social, psychological and educational services and support to the families in need
- Make families participate as active agents in providing care and services to the ill child

- Strengthen the group spirit among the families of sick children by organizing group discussions, excursions, cultural meetings, etc.
- Provide families with coping mechanisms for their different anxieties
- Offer mediation services provided by social workers, psychologists, social assistants, family workers, teachers, etc.
- Promote educational and training programs for survivors in need in order to facilitate their educational, social and professional integration
- Reduce the fare rates for public transportation
- Support survivors by giving scholarships for high school and University studies
- Establish a library in order to provide better information about the disease to children and their families
- Inform parents about their rights and duties with regard to the process of treatment and the kinds of support that are available.

Conclusion

It is evident that each country, or category of countries, has its own family policy system and at different stages with regard to the implementation of the needs previously mentioned. That is why, all we can do as parents organizations, is to express fundamental needs and expect that each member would seek the appropriate formulas and procedures to implement them. The dosages of these procedures vary from one country to the other. Anyway, our duty is to express what we need and do the "plea" for its adoption in the social and political sphere. The way it should be fulfilled must be left to "technicians".

Mokhtar El Harras, "L'Avenir" Association, Rabat, Morocco

News from the parent group in Simferopol

Our Dutch friends do their best (and it seems, sometimes even more) to help our children. Together with commercial companies they organize charitable lotteries, conduct the action "CHANGE FOR GOOD".

Some time ago we asked them to find discharged infusomats as many as possible. These are apparatus, without which up-to-date treatment of oncological diseases is impossible. Infusomats provide the absolutely exact dosage of chemical therapy, protecting mucous membranes of a child against burns. When there is lack of such devices, parents have to sit at the child's bed around-the-clock and count every drop of medicine.

Infusomats in our department have been working for 10 years and totally exhausted their resources.

From beginning of December of last year till middle of January Sergei and Karina actively sought for discharged infusomats. Unfortunately the only ones they managed to find in the clinic were in such worn-out stage that usage of such equipment would be dangerous for patients. They are no longer used in West-Europe. The cost of one new infusion system starts from 1400 EURO.

Nevertheless Karina and Sergei now negotiate with the company "B.Braun" about the possibility to donate several infusion pumps to Simferopol children's haematology. Time will show the results of these negotiations.

It is difficult to choose words for expression of our gratitude to these people for such great and unselfish help!

Parents Initiative Crimia www.hematolog.vinchi.ru
Email: hemato@simfi.net

Announcements

ICCCPO Parents Meeting and Annual Assembly:

17 - 18 September 2002. Porto, Portugal.
This meeting will be held in conjunction with SIOF 2002. See page 11
For further information, please contact Christine Wandzura - details on the contact page

SIOF 2002 - 34th Meeting of the International Society of Paediatric Oncology
18 - 21 September 2002. Porto. Portugal
Themes: Brain Tumours and New Modalities of therapy.

Congress Secretariat:
CONGREX HOLLAND BV
P.O. Box 302
100 AH Amsterdam
The Netherlands
Tel: +31-20-5040-208
Fax: +31-20-5040-225
Email: siop2002@congrex.nl
Website: <http://www.congrex.com/>

PAPOS 2002

10th International Conference of the Pan-African Psycho-Oncology Society
5 - 7 October 2002. Pretoria. South Africa
Theme: A Quest for Quality of Life with Cancer.
[Note: this conference is mainly focused on adult cancers, but should have some papers related to childhood cancer].

Organisers: Superior Conference Management
184 Ronel Street
Doringkloof.
Centurion. 0157
South Africa
Fax: +27-12-667-2540
Email: msdt@yebo.co.za

2nd SIOF-Asia Conference 2002:

22 - 24 November 2002. New Delhi, India
There will be a meeting for parents held in conjunction with this meeting.
Organising Secretary: Prof L.S. Arya
Department of Paediatrics, Division of Paediatric Oncology.
All India Institute of Medical Sciences
Ansari Nagar.
New Delhi 110 029
India
Tel: +91-11-659-4610, 686-4851; Extn 4610, 4390
Fax: +91-11-686-2663
Email: lsarya@aiims.ac.in

6th World Congress Psycho-Oncology

Banff, Alberta (Canada)
April 23-27, 2003
c/o Psychosocial Resources
Tom Baker Cancer Center, Alberta Cancer Board
1331-29 Street NW Calgary
Alberta, Canada T2N 4N2
www.capo.ca

Miscellaneous

Note this change of address:

SIOF - Secretariat

International Society of Paediatric Oncology
Tongelresstraat 88
NL 5613 DM Eindhoven
Netherlands
Tel. +31 402697544, Fax:+31 402697545
e-mail: secretariat@siop.nl

Making a Mark

Is an exhibition of art by children touched by cancer and blood disorders organized and supported by the Texas Children's Cancer Center and The Periwinkle Foundation.

Entries must be from children who have been treated for cancer or blood disorders, or from their brothers and sisters. Parents may enter works of children who have died of cancer or related blood disorders. Each Child who submits an entry will receive one free "Making A Mark"-T-shirt on or after Sept. 8, 2002.

For more information contact:
Texas Children's Cancer Center
Attn: Carol Herron
6621 Fannin, CC 1410.00
Houston, TX 77030-2399, USA

Patient guide helps to demystify clinical trials

A new reference guide has been developed to help patients facing a serious or life-threatening illness confronting the question: "Should I enter a clinical trial?"

More information about this Patient Reference Guide for Adults can be obtained on the websites: www.ecri.org or www.aahp.org

Visit ChemoAngels.com

You can make a difference! Join the growing group to support people with cancer. For details see the Web Site at: www.ChemoAngels.com

Funding Guide for Child Welfare NGO's in Europe and Across the World

(European Forum for Child Welfare Publications, Bruxelles, April 1999, ISBN 2-930269-10-3) is said to be a valuable help for all groups involved in fundraising. Unfortunately we were not yet able to obtain a copy, but as soon as we are, we will give a more detailed report.

Better Medicines for Children

The European Commission proposed a regulatory action on paediatric medicinal products. It is a well known dilemma that the majority of medication applied to children are not officially tested and approved specifically for children. According to current international law most of the chemotherapy used in treating childhood cancer would have to be taken from this specific use. However, drugs used in standardized protocols are well „tested“ and thus proven effective for children throughout the years and should be considered safe. The discussion with respect to this issue involves clinicians as well as patients. We reprint the letter by Prof. Stevens, President of SIOP Europe, to the EU on this matter.

European Commission
Paediatric initiative
To the attention of Emer Cooke
Brussels

12 June 2002

Dear Emer Cooke

Re: Better Medicines for Children – consultation document February 2002



I write in my capacity as President of the International Society of Paediatric Oncology in Europe (SIOP Europe). This Society represents the majority of clinicians engaged in children's cancer care in Europe. Membership is multi-disciplinary and includes paediatric oncologists, surgeons, radiation therapists, pathologists, scientists and epidemiologists. The principal aims of the Society are (1) to facilitate medical, scientific and educational co-operation throughout Europe in the context of the care of children with cancer and (2) to promote and support collaborative clinical trials within European countries.

Our members are well aware of the inconsistencies in current legislation relating to drugs used in paediatric practice. Many of us have experienced the frustration of being unable to evaluate new cancer chemotherapy drugs in the absence of willingness of pharmaceutical companies to support such studies. Furthermore, despite the expertise available and the generally excellent collaboration that exists within the paediatric oncology community, it is proving increasingly difficult to identify the resources necessary to undertake collaborative international studies across Europe at the level required under Directive 2001/20/EC on Good Clinical Practice.

We have an additional and very important concern in that existing resources are entirely inadequate to match the expectation of our members in newer EU countries to be able to participate in clinical trials of new cancer treatment even to the level of that currently possible in countries such as Germany, France and the UK. The development of

clinical trials across the EU to GCP Levels will require considerable additional resource. It is likely that the most cost effective way of achieving this objective will be to support the development of clinical trial network within clinical specialties across the EU. If achieved, such networks would have the structure, stability and professional credibility to work with the Commission and with pharmaceutical companies to agree and implement prioritised work plans directed at the improvement of treatment of children throughout Europe.

In conclusion, SIOP Europe welcomes this consultation document and would wish to take an active part in future discussions about the steps necessary to improve regulatory action and to encourage high quality clinical trials in children, particularly children with cancer.

I hope these comments are helpful. Please do not hesitate to contact me if you would like further information about our work or if you would like us to contribute to future discussions in this arena. Moreover, as there is increasing collaboration between SIOP and ICCCPO (International Confederation of Childhood Cancer Parents' Organisations) who, as representatives of the affected children and their families, would no doubt be keen to work with the Commission and professionals to improve access to new drugs and obtain better support for clinical trials in paediatric oncology

Yours sincerely
Professor Michael Stevens
President of SIOP Europe

Preliminary Schedule for the ICCCP0 – SIOP Meetings Porto Portugal September, 2002

Date & Time	Saturday 14	Sunday 15	Monday 16	Tuesday 17	Wednesday 18	Thursday 19	Friday 20	Saturday 21		
Venue	Hotel	Ibis Hotel Board Room	Ibis Hotel Board Room	Parents in the Novotel Conference Room With survivors	Europarque Congress Centre Survivors in the Ibis Conference Rm 1/2 day	Europarque Congress Centre Survivors in the Ibis Conference Rm full day	Europarque Congress Centre			
Transportation	On your own	Not needed	Not needed	Buses only for evening dinner at the wine caves	Buses	Buses	Buses			
Early Morning	EC members arrive	EC meetings 09.00 – 12.00	EC meetings 09.00 – 12.00 CCCPO delegates arrive	(2) ICCCP0 Opening Ceremonies 09.00-0915 (3) Lectures 09.15-10.15	SIOP registration Open & Posters Placed (8) Interactive Board Session 09.30-11.00 Room S8	(13) Camp Session 09.30-11.00 Room S8	(18) PODC & ICCCP0 09.30-11.00 Room S6/7	Check out and depart		
Coffee				Coffee	Coffee	Coffee	Coffee			
Late Morning				(4) Lectures 10.45 – 12.00	(9) ICCCP0 General Assembly 11.30-13.00 Room S8	(14) SIOP/Nurses 11.30-13.00 Room S6/7 EC Wrap-Up meeting Room – to be decided	(19) Psychosocial session Unconventional Therapies Room S9			
Lunch				Lunch with EC	Lunch with EC	Lunch on your own 12.00-13.00	Lunch on your own		Lunch on your own	Lunch on your own
Early Afternoon				EC meetings 13.00-17.00	EC meetings 13.00-16.00	(5) Introduction of Workshops and first round 13.00-14.30	(10) Programs of the Parent's Groups 14.00 15.30		(15) Nurses/ICCCPO Educational Needs of Children with Brain Tumours 14.00 15.30 Room S6/7	(20) Psychosocial session Unconventional Therapies – con'd Room S9
Tea Break				Tea 14.30-15.00	Tea	Tea	Tea		Tea	
Late Afternoon				(6) Second round of workshops 15.00-17.30	(11) Programs of the Parent's Groups 14.00-18.00 Room S8	(16) Nurses/ICCCPO Continued 14.00-18.00 Room S6/7	(21) SIOP/ICCCPO 5% For Hope Initiative Room – TBA			
Evening	Dinner with EC	EC Dinner with Porto Organizing Committee?	(1) ICCCP0 Meet & Greet 18.00 – 20.00 at the Novotel Conference Room	(7) Acreditar hosts Boat Trip of the Douro River and dinner at the Porto Wine Caves. Buses will pick up participants in front of hotels. Departs 17:30 Returns 23:30	(12) SIOP Opening Ceremonies 17.35-22.00 Auditorium Dinner on your own EC with Cairo Organizing Committee	(17) Dinner on your own	(22) SIOP Dinner Palacio da Bolsa 20.00-23.00			
			Dinner on your own							

Executive Committee

Marianne Naafs-Wilstra, Chair
 Showstede 2d
 3431 JB Nieuwegein, The Netherlands
 Tel. +31 302422944 fax +31 302422945
 e-mail: mc.naafs@vokk.nl

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

Christine Wandzura, Secretary
 Kids Cancer Care Foundation of Alberta
 609 14th Street, NW, Suite 205
 Calgary, Alberta T2N 2A1, Canada
 tel. +1 (403) 216-9210, fax +1 (403) 216-9215
 e-mail: wandzura@kidscancercare.ab.ca

Mark Chesler
 University of Michigan, 4028 LSA Building
 500 South State Street
 Ann Arbor, Mi 48109, U.S.A.
 tel. +1 (734) 64-3654, fax +1 (734) 763-6887
 e-mail: mchesler@umich.edu

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

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

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

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

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

Members of other ICCCPPO committees:

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

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

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

After the death of my dear husband Henk I received many, many cards and e-mails from all over the world. My children and I want to thank you for your warm sympathy. Knowing that so many think about us really helps us through this hard time.

Marianne Naafs-Wilstra