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## News from the Board

### Meetings

The recent highlights of our organization were the international meetings in Portugal, India and Brazil. Continental meetings such as SIOP Asia, Africa and Latin America are important occasions to promote paediatric oncology in developing nations. The collaboration of health care professionals and parent organisations in a so-called Therapeutic Alliance is probably the most effective way to improve the care for children with cancer and their families in these countries. ICC-CPO supports the building and maintenance of parent organisations. If you wish more information or want ICCCPO 's help to set up a parent organisation in your community, please check our website ([www.icccpo.org](http://www.icccpo.org)) or send an email to our Secretariat ([icccpo@vokk.nl](mailto:icccpo@vokk.nl)). The ICCCPO website contains not only information about our confederation but also provides articles, guidelines, practical tools for parent groups, an annotated resource list and our annual report.

### Guidelines for Standards of Treatment and Care

Around 200,000 children worldwide get cancer each year. The economic and cultural background of a country will have a significant effect on the standards of treatment and care a family receives.

In more developed countries, children will be diagnosed early and receive treatment according to a standard protocol. Because of the work done to create national and international collaboration on treatment, some 70% of these children may be cured. In less developed countries, most children either do not get diagnosed, or receive



The new ICCCPO-board

inadequate treatment. Overall, some 80% of children with cancer fall into this latter category.

As a result, around 170,000 of children with cancer die each year. Over 100,000 of these deaths would be preventable, if all children had access to standard treatment.

The most basic instinct of parents is to protect their children. Life threatening illness in a child therefore presents the most traumatic experience a family is likely to face. This trauma presents itself both socially and psychologically. And so, an integral part of treatment must be the care provided to help a family through the experience and to re-integrate into society afterwards.

Although levels of care are being developed around the world, it is not coordinated in the same way treatment is. Furthermore, measuring success in care can be largely subjective.

Nonetheless, when the complexity is taken away, when there is now a good chance of saving the life of a child with cancer, they deserve to receive treatment; and the family as a whole should have the right to go through that treatment with minimal affect on the rest of their lives.



Delegates at ICCCPO-meeting from all over the world

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**Marianne Naafs-Wilstra,**  
president

These families have only one chance to deal with the illness. Most who have taken the journey are able to look back and reflect on what they might have done differently.

ICCCPO has developed a paper that examines what families should expect in terms of standards of treatment and care. At the meet-

ing in Porto, ICCCPO and SIOP will collaborate on further development of this document. The standards might provide parent organisations and professionals a map to help individual families take an informed journey.

### **New members to the board**

At the most recent conference we elected two new members to the executive committee:

Edith Grynszpancholic from Argentina and Ira Soelistyo from Indonesia, thus having representatives from two very important areas with us on the board. We wish them luck in their new positions.

Marianne C. Naafs-Wilstra  
Chair



## **International Childhood Cancer Day 2003**

The second ever International Childhood Cancer Day (ICCD) will take place on Saturday 15th February 2003. ICCD is your organisations chance to EDUCATE your community about the issue of childhood cancer and tell people about the valuable activities that your organisation carries out attract NEW SUPPORTERS to give their time, money or services to your cause MOTIVATE existing staff, volunteers, members and supporters by getting them involved in fun events

Cancer Research UK is continuing its support of ICCD by sponsoring the event in 2003, by making a donation to ICCCPO and producing and distributing an ICCD fundraising and media pack to all the member organisations taking part. (English and Spanish versions) The pack includes information on

- How to raise money by organising a fundraising event
- Fundraising event ideas
- How to use the media to promote ICCD 2003, and the work of your organisation
- Childhood cancer statistics

If you have not received your pack contact the ICCCPO coordinator (Geoff Thaxter) for the ICCD at [info@lisathaxter.org](mailto:info@lisathaxter.org).

New for this year is the ICCD microsite on Cancer Research UKs main website, this will be live from 6th January 2003 and include:

- Information about ICCD
- What is childhood cancer?
- Case studies from around the world
- Message board
- Links to press releases
- Children's educational and interactive games corner
- Fundraising and media pack for you to download
- [www.cancerresearchuk.org/childcancerday](http://www.cancerresearchuk.org/childcancerday)

At our Porto conference Lucy Machin from Cancer Research UK presented a workshop on how to organise an ICCD fundraising event and promote your organisation and the event using the media. Lucy said, "It was really great to visit Portugal and have the opportunity to meet with parents from around the world. Cancer Research UK is delighted to be working with ICCCPO again, and sees this as a chance to build on the achievements of the first ICCD with the aim of helping thousands of children around the world. The key to a successful fundraising event or media campaign is planning ahead, the pack will help you to start thinking now about what you want to do, who will be involved and which contacts you need to make. Don't forget to let us know how it goes by filling in your evaluation forms after the day. Good Luck!"

## Executive Committee – 2003

### Can you help children with cancer?

Nominations are sought for the Executive Committee of ICCCP. If you are already actively helping children with cancer in your own country, do you have the energy to help these children internationally?

### What kind of person is required?

To work effectively, the ICCCP Executive Committee wishes to be made up of people that:

- Represent our wide membership
- Bring new skills to the board
- Are energetic and have time to commit to the role
- To be eligible you must also be part of an ICCCP member organisation.

### What is the commitment?

Election to the Executive Committee is for a 2-year period and then can be subject to re-election. So, you should be prepared to commit time to the role for a minimum of two years.

Typically, you will find as an EC member you need to give around 4 hours a week to the role. You will also attend:

- Two EC meetings a year
- Take an active role in the AGA
- Attend occasional Regional events

### Not sure? Want more information?

If you would like to find out a bit more, please contact Geoff Thaxter at [info@lisathaxter.org](mailto:info@lisathaxter.org)

### When do the elections take place?

The next elections will take place at the 2003 AGA in Cairo, in October 2003.

### When do nominations need to be in?

As soon as possible, but the closing date for is 30th June 2003.

Send applications to Geoff Thaxter

[info@lisathaxter.org](mailto:info@lisathaxter.org)

Federazione Italiana di Oncoematologia Pediatrica

## MILAN MOTION 2002: 5% for Hope

Whereas the Parents' Associations of Pediatric Oncology affiliated to the FIAGOP have met in Milan at the Convention Center of the Cariplo Foundation to celebrate the **"First International Childhood Cancer Day"** as part of the great family comprising children, parents, friends, volunteers, health operators and all those who in a variety of capabilities have met and cared for a child with cancer, whereas great progress has been made in the last 30 years in the treatment of children's cancer leading to a cure in 75% of cases, the Parents' Associations have played a key role in mobilizing resources to support:

- an increasingly broad application of "global assistance"
- improvements in health structures
- clinical and biological research

all this in the spirit of a "Therapeutic Alliance" between families and health operators.

On the contrary over 80% of the children stricken with cancer live in Third World countries where the access to effective treatment is often unavailable, thus eliminating any hope to be cured where the resources required to ensure adequate therapeutic standards and to promote research are increasingly inadequate due

to escalating costs and limited investments in Public Health both in Third World countries and - to some extent - in developed countries as well.

The Parents' Associations of Pediatric Oncology make a petition to the national Health Authorities, the government and non-government organizations at national and international levels, and all persons of good will for continuation of their support to the Associations' programs in the fight against cancer in young children.

The Parents' Associations also request the Italian Centers of Pediatric Hemato-Oncology to identify specific projects to improve cooperation with similar centers in Third World countries, where they exist, or to create new centers, where they are not available.

In support of this effort, the Parents' Associations are planning to implement the program "5% for hope" which includes the allocation of 5% of their annual budget to finance:

- a. twinning programs between Centers of Pediatric Oncology in Italy and similar Centers in Third World countries and
- b. "sponsor a child" programs for children stricken with cancer.

FIAGOP - MILAN, 19.01.2002

Elfi Schattauer

## It's over – Is it over ?

Your child became ill many months ago, or was it years? The diagnoses: cancer! You accompanied your child through long months of therapy. The therapy is finished now. Your child has survived.

Nevertheless, nothing is as it was before. The time of illness has left deep impressions on you, on your child, your family and your relationships to one another.

"A cancer diagnosis in any member of the family imposes change, disrupts the family's homeostatic balance and unsettles the operational guidelines for interpersonal behaviour."

Today about 75% of all children and young people suffering from cancer in developed countries can be cured. For parents and the child, this progress and improved prognosis not only means hope for cure and survival, it also means the necessity to deal with the problems and issues, the child suffering from cancer will have to face in the future.

Often years after the completion of the therapy the parents of cancer patients who survived show symptoms of posttraumatic stress, statistically even more often than the patients themselves.

Studies have shown that most parents continue to worry about their child's condition from five to twenty years after the illness ("Damokles-Syndrome").

After the end of intensive therapy, which usually consists of long periods of hospitalisation, bringing additional problems, it takes a long time for the family life to get back to normal. During this time of hospitalisation, the clinic becomes a familiar environment, where the staff has managed to convey a feeling of security. Parents often feel left alone once their child has been discharged from hospital. They have the feeling that "the ground has been taken from under their feet". The family is now physically closer, however personal closeness and affection often has to be built up again and worked on. The physical and psychological state of exhaustion that parents have felt through the intensive time but were not allowed to live out breaks through the barriers they had put up. Their energy reserves are often exhausted. Their own physical ailments begin to surface. Everyday life becomes controlled by irrational fears.

Parents report having psychosomatic problems such as insomnia, loss of appetite, digestive problems, headaches as well as the fear of possible relapse or contraction of another form of cancer. Many parents are worried about the possible negative side effects resulting from operations, radiotherapy or chemotherapy. Source of worry for some parents are the difficulties faced by their son or daughter in seeking employment and in signing for life- or health-insurances.

### All parents regret the neglect of the siblings.

Earlier conflicts of the partners, which became unimportant during the time of acute illness, and problems, which lost their intensity during the time of illness, come to the surface again, demand a solution.

Furthermore, as time goes by, there is less understanding by those surrounding the families of the former patients, their families and their problems, which are connected with the earlier illness, because the illness is gone such a long time ago.

From the experience of recent years one can estimate that about 30% of the parents suffer from somatic and psychosomatic symptoms and illnesses.

Originally this means for us as "Kinder-Krebs-Hilfe" (Children's Cancer Aid) providing a setting where parents are given the opportunity of dealing with the issues of returning to 'normal life' and offer the help necessary to make this possible.

### Treatment concept of the oncological aftercare concerning the aspect of posttraumatic stress disturbances

Based on these reasons and encouraged by a program of the children's clinic in Philadelphia (Surviving Cancer Completely Intervention Program) the Austrian "Kinder-Krebs-Hilfe" has organized a weekend program for the parents of children and teenagers formerly suffering from cancer in cooperation with the oncological outpatient department.

This weekend program is offered twice a year (from Friday evening until Sunday afternoon). The seminar for the parents comprises of groups each made up of 16 to max. 20 persons.

The first evening is set apart for reflection upon ones own family situation and the changes one would like to make. Already here it became obvious, that despite the different ages of the children and the different diagnoses the problems of each family are very similar. One main theme was finding the right balance between the closeness or distance in the relationship to the child, the parent and to the hospital.

On Saturday the first part is focused on the relationship and experience with ones child. The aim is to become aware of the child's strengths and abilities and to gain confidence in their ability to cope with the future.

The second part deals with working on the difficult traumatic situations the parents faced during the life-threatening stage of the illness and the psychosocial

experiences they went through afterwards. This is presented theoretically and then the parents (divided in separate groups of men and women) share their experiences. Finally partners take part in a communication training.

On Sunday everyone tries to work out for him/herself concrete steps he/she could take from what was heard and experienced during the seminar. Elements of the seminar are apart from the cognitive experiences also hypno-therapeutic techniques, movement and creative actions.

In the planning of the program it was made sure that sufficient time would be available for informal exchange among the parents. It becomes obvious how difficult it is for parents, after the shock of hearing a life threatening diagnosis and the difficulties that accompany the necessary treatment, to cope with the physical and psychological effects of the illness, which affects them, the child as well as the whole family.

#### **Aims:**

Reduction of posttraumatic stress-symptoms caused by the cancer diagnosis and its therapy for the whole family

Reflection and 'working through' the early cancer illness of the child

#### **Themes:**

- fears
- understanding of cancer and treatment
- social support
- family communication as a specific area of change

In order to give closer insight into the reason, why we like to continue offering these seminars, we asked the participants to share their experiences. We asked four questions and requested that partners answered independently from each other. There were encouragements to answer the questions as spontaneously as possible and not to prepare beforehand what they would write.

## **THE QUESTIONS**

### **Question 1**

What motivated you to take part in this weekend ?

**Mother:** Return to normal family life. To have the same positive experiences, which my child made during seminars for young people, in order to benefit for the family life.

**Father:** Share with those who have had to face similar situations. To get answers to questions one feels left alone with.

### **Question 2**

What comes to your mind by the headline: "It is over! – Is it over?"

**Mother:** No, nothing is over. The anxiety continues to grow and one tries to suppress it. Thoughts like:

What have I done wrong during the therapy and especially now after the therapy, never go out of one's mind. How can I live with this stress and nevertheless improve the family situation, while not always controlling the other members of the family.

My anxiety – could the illness reappear or who will be the NEXT one – could be transmitted to the family.

**Father:** It is perhaps a period of life experience that's gone, but it is never over!

The family members and the internal family structure begin to readjust to everyday life. Everyone works through the issues of cancer differently. This leads to different positions in the family causing quarrels without reasons and this can unconsciously influence the productivity at work. In the family circle these problems are rarely, if at all, talked about, because: lack of time. If there is time it does not happen at the flick of a switch; everyone has his own problems which are important to him, so nobody is really able to listen to the other.

### **Question 3**

Have you noticed any specific changes after the seminar either within the family or with outside contacts (friends)?

**Mother:** I have learnt TO LET GO and not only with the ill – now healed – child, but especially with my other child. Both cope now with their own problems by themselves. I am, always there when THEY need or want me. The issue cancer is no longer in the foreground of our talks.

Shortly after the seminar I was in a bad state both psychologically and physically. I realised how much I had suppressed instead of having worked out. But now sometime after, I feel that this was good. I learnt to work through, to face every situation, however painful it may be.

**Father:** Somehow I felt good afterwards. One is not alone, there are other parents who are in the same situation. After the seminar I could look at our family situation from a birds-eye perspective and this gave me a certain objectivity in the way I saw the situation. At least I have learnt to reflect on inside feelings with a certain distance.

### **Question 4**

What would you like the "Kinder-Krebs-Hilfe" parents organisation to do for parents after intensive treatment is over?

**Mother:** These seminars should take place immediately after the end of the therapy. They didn't exist then and for our family (except our ill son) there was no, or almost no kind of working-through-process.

**Father:** Well, a second one, to be able to share experiences with other parents again while at the same time getting competent advices from specialists.

Many things we learned and picked up in the seminar have been either forgotten, pushed out or not been integrated enough into our daily family routine. Through this seminar some things were brought back to us and refreshed in our memory.

**The next seminar will follow in Spring 2003.**

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Edith Grynszpancholo

## Facing a big crisis – Creative management of resources

Our organization had a great growth last year. Since the year 2000, we have a new center in front of one of the big pediatric hospitals of the city. We received 200 new families in 2001. We are well known and the pediatric oncology community sees us as a valuable resource. Never like now, poverty, hunger, violence and insecurity are spread in our country. I would like to talk about what we do about this situation, as the resources are scarce and we must pay attention to every possibility.

The objective of this presentation is to show the different ways we found to cope with this crisis. We think it could be interesting for parents groups in developing countries.

I will talk about the way we manage the donations in kind we receive and, on the other hand, how we manage the explosion of people that come willingly to our institution wanting to help others and how we coordinate their intentions or expectations with our mission.

### **The crisis in our country had affected the care of the children with cancer in different ways:**

Most of the families that come to us, almost 80%, are unemployed for a long time, often more than a year. Many times, they don't even have the money to reach the hospital or to buy any food. We used to have a "free pass", given to the child during treatment. Now, because of political misunderstandings between "sectarian powers" we lost this benefit, making transportation a big problem. Most of the patients live far from the hospital, or have to come from other states. They lack the money for food, so the nutrition level of some of these children is very poor. The governments of the other states of our country are broke, so they don't let the families come to Buenos Aires to get the specialized attention they need, even if it was necessary. The Bank of Medicines, a state agency that has to give chemotherapy and other medicines free, very often has nothing. Some medicines, that are imported, are so expensive that people cannot buy them at all. We import the Procarbazine and distribute it all over the country free. At this moment, it seems that nobody is responsible of the situation, even knowing that our law says that "free health services must be available at

every public hospital ... " Many hospitals, most of them from the interior, have no medical supplies at all for those families, which have medical insurance, the situation is not much better. Although, we have a PMO, medical obligatory program, insurance companies try not to pay. So, for every patient, we have to contact a voluntary lawyer or public prosecutor, to make them pay.

### **Because of the crisis, our donors also changed their way of giving:**

Individuals want to make gifts "in kind", rather than giving money. It could be for making it friendlier, or because they want to be sure that the patient receives the goods: they ask us what we need, and then they buy it. Maybe they don't want "just" to give money. Many families, friends of our Foundation left the country, and they gave us the house ware. Since December, the solidarity has a great growth. Many groups raised money to buy things for people in need: people from the same building, work, schoolmates, friends, religious community, grand parents, and patients from other institutions work together. The shops and industries are in a very bad situation: they used to give us money but now they only offer some of their services or products. Some of them broke down and closed their doors and ask us to get whatever could be useful for us. The "corralito" made people not to have cash to give in contributions. Even the State gives us thousands of things from customs since the price of the dollar changed.

### **First of all, I need to explain to you what "Trueque" is in Argentina.**

People sell their things and receive a check, called "crédito", it's almost like peso, our money. With that check, they can buy other things at the same place, or in other similar "nodo". It can't be used, for example, to pay for public transport. People used to change things from their house, but at this moment they have no more things to change. There are a lot of articles in newspapers about trueque. One of them said that almost 6.000.000 Argentineans live from trueque, and since last summer, a lot of people go there, looking for food. We decided to start helping in that way because many of the families told us their experience. We brought all the information together, parents can read

it in our house, or they can share information between them, through a folder where everybody writes about their own experience.

We established a deposit, it is open twice a week, near our Foundation. There is one responsible person and two volunteers. We prepare a bag, worth around 120 créditos. Parents can look for it every 10 days. At this moment, almost 140 families are doing Treque, with our help. Things in the bags are quite beautiful, and we also try to give people things according to their need, abilities or skills. Parents bring the things they do back to show us.

There are also additional benefits for these families, when we help in this way:

- It's not just a gift. They can make it worth more, depending on their own ability to exchange.
- It's an alternative job. Taking into account the lack of time during treatment, this is an activity that can be done whenever possible, near each house. They feel free of doing it, just when it is possible.
- It brings also some new entertainment for the child, he or she sees his/her parents doing something that makes them feel better.
- They always receive very useful things, very easy to sell. As many times these goods are new, they can change it for the cash they need, e.g. for transportation.
- They also sell the things they do at our creative workshops.

### How do we manage the cooperation of the people?

#### FOOD

- Daily, we serve some of the meals to these - families, for those that are more in need, we also give a bag with basic foods.
- a volunteer started teaching Soya cooking
- when going to the supermarket some women buy at the same time food for our foundation
- neighbors collect food and bring it to our house
- factories give us the products that are near the date of expiration.

#### DRUGS

We have a set of frequently requested medicines that we try to have in advance . Due to the situation we try no to buy them, just get it from other sources.

We work on parent's awareness, talking about the responsibility of giving back the medicines when it is possible.

On the other side, we use the media to sensitize the general public about giving drugs they might have at home (we call it recycling ).

Some of our volunteers work on asking the laboratories for drugs for a specific patient

As a new way of helping, a group, lead by a mother, is collecting newspapers, selling them for recycling and using the money to buy medicines or medical supplies needed at the hospitals.

#### HOSPITALS

Some people approached us to help at the pediatric hospital. We tried to organize them, we created a special fund with the money they raised, and kept it available for the help they want to give. They learn of our experience. Usually, they get the information about who could make a contribution and we make the formal presentation and administrate the funds.

- At the moment we have two groups of this kind:
  1. A Group that Supports Research in Pediatric Oncology: They are parents of survivors, children treated at the Hospital Garrahan, all of them are out of treatment. They try to raise money, get other parents involved, organize meetings or events and work with the media.
  2. A Group that Supports Hospital Posadas Pediatric Oncology Department. Two mothers, whose daughter and son died, lead it. Recently they got the money to re-build part of the ward area and they are a better link with the families of that hospital, which is far from our house. These mothers come to us looking for the things family and hospital may need. Parents don't have to travel so much to get our services.

#### This year, we realized that urgent needs worried our families and

We have other programs and objectives. We are not proud of having to do these kind of activities, so we also make great efforts to keep doing our best in other areas like recreational activities, academic area, work shops, and parents support. For example, we have been invited to join the "Traveling Team" formed by the Oncology Committee of the Pediatric Society of Argentina. This is an interdisciplinary group that visits all centers in Argentina dealing with pediatric cancer with the aim to asses the situation, improve standards of care and create a national network to regulate, standardize and coordinate oncology practice in every region. At this moment, we have links with all the institutions that treat childhood cancer.

For those Spanish speaking nations or patients, I want to inform you about our translation of the SIOP Guidelines of the Psychosocial Committee into Spanish, which is available through the web page of the ICCPCO.

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Marina Novitskaja

# Experiences of a parent organization in crisis conditions

This article was prepared for the ICCCP0/SIOP-meeting in Porto but not presented

## Our situation

Our organization works in a region of the Ukraine, which has the status of an autonomous republic. We live in the Crimea peninsula which is a unique geographic and natural region. After the collapse of the Soviet Union, the government of the Ukraine started to return the state to a capitalistic way of life and production. But the matter is that the psychology of the people, which are not used to be masters of their own lives, cannot be changed as fast as it is necessary. The citizens of the Ukraine should have free medical service (as it was in the Soviet Union), but the truth of daily life reveals that in a situation of general crisis the state has no possibility to carry out this obligation. It means that the state can provide only 30 percent of the full price for the treatment of a child with an oncological disease, namely: a free bed in the hospital for the child and his/her mother, free medical examination and the main part of medical manipulations. The state also provides free teachers in the pediatric departments of hospitals. But all the rest: medications, all food necessary for adequate nutrition (for the children and the parents in the hospitals) and complex medical manipulations and tests – these expenditures are paid by the parents.

The treatment of one child depending on the kind of the oncological disease can equal to five or ten thousand dollars, and this sum is to be paid by the parents. Sure, according to European and American standards, this is not a fortune. But for the parents in the Ukraine sometimes this sum is almost astronomic. An average monthly salary/payment in the Ukraine equals 40-100 US\$. Sixty percent of the children admitted to onco/hematological the department of the Crimea Republican Children Hospital are children from families with such income. And there are also children from families with worse financial status as well as orphans. Unfortunately, it often happens that as result of oncological diagnosis of the child the family falls apart. Often the father leaves the family, thus the income of that family is reduced by one half.

Such situation has only one way out – charity. But 80 years of communist regime destroyed the traditions of charity, which were strong in the Russian empire. Due to the general crisis in the country the development of new charity traditions is very slow and is connected with many difficulties. The state gives no help to potential charity movements, providing no tax remissions for the enterprises that show charitable activity.

Now different kinds of public organizations develop and public activities of the citizens are growing very fast in Ukraine (NGO). This progress became possible due to support of European and American organizations, which organized the training of Ukrainian citizens in the field of public organizations and foundations. But our country has no experience in this respect, such as the foundation of an organizations by parents of sick children. Unlike any other public, religious and educational programs this side of public activities is never covered by the foreign training projects. Maybe it is possible for ICCCP0 to organize seminars of that kind in states of the former Soviet Union.

Due to extreme costs, the internet can only be used by very few people. However the internet is a very important tool in communicating medical information.



## Cancer – still a taboo

A taboo on the diagnosis cancer existed in the Soviet Union for many years. It was prohibited to tell this diagnosis to the patient. Citizens of post USSR countries have not only the stereotype idea: "cancer means death", but also are not willing to accept any information about the disease. The collapse of the Soviet system of health service and prophylactics of different diseases as well lead to the fact that oncological and other diseases are diagnosed too late. Such situation is twice dangerous in the Ukraine, home of Chernobyl. The main part of the population of the country knows absolutely nothing about the curability of cancer. I can tell you this with all my experience because five years ago my family and I belonged to this part.

The lack of such information gives the ground for different charlatan healers to appear. During the first month when the diagnosis "cancer" is approved, the parents of the sick child are literally attacked by the



crowds of different charlatans and representatives of net marketing groups, selling shady "heal-everything" new medicines and bio-additives. Parents, which are frightened to death by the diagnosis and full of doubt to state health services, often let the first charlatan healer persuade them to give up conventional chemotherapy. Unfortunately neither our doctors nor we know any of the cases when healers cured the sick child.

One of the problems of pediatric oncology in the Ukraine is the absence of possibilities to do bone marrow transfusions. Great work is done in this field, we have talented specialists, but we need time for their full training and qualification and for organizing our own donor bank. Unfortunately, time is the thing that our sick children never have. That's why contacts with parents and other public organizations abroad are so important for us. In 1998 due to the support and great work of Dominican monks from the Catholic Church in Yalta and parents from an Italian parents organization (we got their address from the ICCCP0-Newsletter) we had the opportunity to send a 5-year old boy to Italy to undergo the bone marrow transfusion. The operation was paid by the Vatican. The transplantation was successful, but the boy's organism was too weak and he didn't survive hepatitis.

**Rehabilitation**

Many problems are connected to the almost non-existing system of rehabilitation. First of all, there is no psychological support during the treatment and afterwards. In the Soviet Union the help of psychoanalyst and psychologist was not considered as vital and important. Moreover, it was treated as something shameful. Soviet people were not allowed to have psychological problems. That's why now in the Ukraine we have only a few psychologists, which can provide real support to the sick children. In the oncology department, where psychological support is a question of vital necessity for children, their parents and doctors as well, the situation must be changed as soon as possible.

It is necessary to persuade the poor state that it is important not only to cure the sick child but also to give him/her the opportunity of rehabilitation, to reconstruct the health, to become a real member of the community and to be realized as a person.

In the same line we see the chance to give school education to children with leukemia. These children cannot visit the school until the treatment is finished. The Ukrainian Law provides the opportunity of home education, and the child is supposed to be taught by the teachers from the school he/she visited before the treatment. But unfortunately, the Ukrainian education system has a lot of other serious problems, that's why home-educated disabled children are usually left alone with their problems.

We are very lucky that we don't have any problems with the doctors. Here, in Crimea we have a very qualified group of pediatric oncohematologists. Ten years ago on their initiative a leukemia group was founded in Ukraine, it is supervised by professors from Germany. These selfless people do all their best for each child in the hematological department. The problem is in the following: the whole department staff, forty five specialists get a monthly salary (TOGETHER!!!) which equals the salary of one nurse in Germany. The doctor, the specialist of European qualification, working in the state clinics, is paid by the state forty dollars a month.

Almost all our Ukrainian health service is infected with corruption, and if you want to be cured, you have to pay private and make expensive presents. But we never meet the backside of our state health service. The specialists of our department realize their duty in the highest sense of the word. But they have their own families; they have to take care about the future of their children. We are afraid that they can change not only their occupation but their country as well, as it has already happened. Last year we lost one of our best doctors who moved to the USA.

**Organizing a parent group**

In 1991, on the initiative of the head of the hematological department of the Crimean Republican Children's Hospital, Valentin Usachenko, the organization for parents of children with oncohematological





diseases was founded. Valentin Usachenko is a specialist of highest qualification, great doctor and a great person. Usachenko trained in Germany and witnessed the work of the Parents Initiative there. In 1992 the organization of the same kind was founded in Simferopol and worked successfully for several years. The first years were difficult in the beginning of Ukrainian independence, times of chaos. But the organization made great progress. It got the medications for therapeutic protocols, got the permission (on the state level!) for one of the parents to stay with the child during treatment, gave support not only for small patients, but medical staff as well.

In 1998 a group of parents founded the "Mercy Mission Overcoming" with Dr. Usachenko as supervisor. We coordinate with him almost all activities of the mission, because he usually knows better what is really necessary for our children and how to organize the work to fit with the daily schedule of the department and the hospital.

The main part of the mission's time and efforts is spent on the search for money to buy medication, medical tools and equipment. Our children are very lucky – our German supervisors send the necessary medications for leukemia therapy to the department. The Simferopol department received this help from German doctors for over 11 year. And we are tremendously grateful to these people, who take care of the health of our children better than the state, to which they belong. But leukemia is not the only pathology. There are chemotherapy complications and obtained hepatitis. All medications are very expensive. Our main task is to provide all children with them.

We decided to do one thing, that became both a part of psychological rehabilitation of children and a way of gaining money at the same time. Our children staying at the hospital are making handicrafts with the help of teacher. They draw pictures, make embroidery and applications, do origami. The results of their work do not stay in the shelves of parents and relatives. We exhibit them on different occasions and sell them. Certainly, comparing with the total sum needed for the

treatment, the money gained from these sales is very small. Part of it is spent for providing our art students with paper, pencils, paint and so on. But the rest is enough for purchasing a monthly supply of some necessary and not expensive medications or solutions for the whole department, or to provide one child with the expensive antibiotics. And the children are really proud – they take a part of the financial burden from the shoulders of their parents!

### Contact to ICCCPO

It is very difficult to explain how important it is for us to be part of the of federation of parents organizations. It can be compared with the condition of parents in the first days when they knew the diagnosis of their child, when they realize that they are not alone, that parents of other children support them and that their child has a good chance to be cured.

### Excerpts of a letter from Skopje:

#### I wish you a successful work in Porto.

Here, in Macedonia, things are still on a level of initiative. In this moment few parents of us are taking part in activities of the general union established by women treated for cancer. Some of these activities are intended to support the pediatric oncology department in Skopje.

I hope that till the end of the year we shall have established a separate society of parents with children touched by cancer and blood disorders.

Until then – with more information and knowledge.

Yours sincerely

Natasha Kotlar-Trajkova

During three years of our work we tried to make our website most informative both in reflecting the state of affairs in our oncohematological department and on parents organization. Now our site is well known in the Russian speaking Internet.

We also cooperate with local mass media. They regularly and free of cost inform the community about our needs, place the requests of the parents about needed help, tell the community about our actions. We'd like to make a regular publications of popular articles about cancer and possibilities and ways of its treatment, but the above mentioned taboo is still alive in the consciousness of people; and editors of our newspapers are just people.

The most grateful field in our work is the organization of festivities for children. Such holidays are the main rehabilitation actions by now. We try to make various programs, involve actors, circus groups, and puppet theatre, sometimes even make a kind of per-

formance by powers of parents, staying in the department with their children. Certainly, all of children are given presents – it's a must! And we are greatly thankful for the families from Great Britain, who sent our children Christmas gifts for the second year running.

### Parent involvement

It may seem strange, but the main problem of the mission is how to involve more parents. Just 1–3% of the parents show interest in the activities of the initiative. The main part of them can be organized for one single event or help. But usually when the child has finished the treatment and is out of the department, the taboo works, and parents try to forget everything that was connected with the hospital, cross out all dreadful months and years off their lives. It is easier to find help and support from people who are not connected with the hospital: providers, designers, translators, journalists, artists, actors – you name it.

### Future goals

We need a centralized search for medications. We need a well working internet platform. We need volunteers to work in the department. We need to train them, introducing them to the specific aspects of this work and to stand the emotional stress. We need psychosocial support for children, parents and the staff.

We have the opportunity to organize a library with special scientific, popular and fiction books that can help in psychological support for children and parents. But our department has no special room and space for it. We need another room in which parents (usually mothers) can stay during the treatment of their child, where they can do handicrafts and other things.

We need a good schooling system for our patients and hope to get support from donors. We got already 2 computers for the department with Internet. The provider allowed us all-day long access to the world web. Microsoft department in Moscow provided us with Windows and Office programs for the specific educational program free of charge. We bought a series of educational programs as well. Now we need 2–3 more computers more and 2 volunteers to assist the children and to coordinate the education process.

Of course, our problems are very familiar to most of people in the ICCCPPO community. One or the other way you have solved them or are just now solving. We will be happy to accept your help, and will be twice as happy if our experience will help you. We are very glad to be part of this community.

*Marina Novitskaja  
Coordinator of Mercy mission "Overcoming"  
Crimea, Ukraine*

## Announcements

### 2nd International Childhood Cancer Day

15 February 2003

(see more information on page 2)

### 6th World Congress in Psycho-Oncology

23 – 27 April 2003. Banff, Alberta (Canada)

More information: [www.capo.ca](http://www.capo.ca)

### SIOP 2003 - 35th Meeting of the International Society of Paediatric Oncology

8 – 11 October 2003. Cairo (Egypt)

Supportive themes: Cancer in the immuno-compromised child, and Renal tumours in childhood  
Main theme: Comprehensive Supportive Care of the Child with Cancer

For details on the SIOP Congress contact:

[congrex@congrex.nl](mailto:congrex@congrex.nl)

[www.siop.nl](http://www.siop.nl)

### ICCCPO Parents Meeting and Annual Assembly

6 – 8th October 2003. Cairo (Egypt)

This will be held in conjunction with

SIOP 2003. More details will follow soon

(see also website [www.icccpo.org](http://www.icccpo.org))

### 6th Continental Meeting of SIOP in Africa 2004

3 – 5th May 2004. Blantyre (Malawi)

It is expected that there will be a parent meeting in conjunction with this conference.

Conference Address: SIOP 2004. Paediatric Dept. College of Medicine.

Box 360. Blantyre. Malawi

E-mail: [emolyneux@paeds.medcol.mw](mailto:emolyneux@paeds.medcol.mw)

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# PODC/ICCCPO ROUNDTABLE, SIOP CONGRESS, PORTO

## Improving Access to Care

Methods to improve access to care were discussed, in particular the influence of instructing primary health care workers in early warning signs of childhood cancer and the importance of immediate referral.

Sadie Cutland introduced the subject. The CHOC Childhood Cancer Foundation provided a salary for a doctor to promote the St. Siluans Warning Signs for Cancer in Children in 4 South African provinces. The foundation also pays for a toll-free telephone line to the Chris Hani Baragwanath Hospital in Soweto, Johannesburg, for advice regarding diagnosis and referral.

According to Stellios Poyiadjis, only about half of the expected 1200 new cases of childhood cancer in South Africa are referred to a pediatric cancer unit, and in the under-privileged sector of the population more than 80% present with advanced disease. Many patients die at home without diagnosis or are not referred.

After giving 50 lectures on the early warning signs and the importance of immediate referral to primary health care workers of 4 provinces, and after distributing 1500 poster in English and another 1000 in Zulu, three big pediatric oncology units draining the 4 provinces experienced a 15-25% increase in the number of patients seen during the first 6 months following the campaign. At Chris Hani Baragwanath draining Gauteng and North West Provinces the number of referrals of hematology and oncology patients increased by 56% (oncology 60%).

This project could not have been realised without the cooperation of the provincial public health care systems. The aforementioned lectures could be given at meetings that were compulsory for the primary health care workers and the instructor could use the address and phone/fax number lists of primary health care infirmaries, clinics and hospitals as well as directories of persons in charge of the different institutions.

The toll-free line was not always used as intended. Initially parents of patients at Chris Hanl Baragwanath tried to use it for personal communications, or the line was used to get informations on non-oncological problems. Despite these difficulties, at least 1-3 relevant calls came in per day.

The question was raised if the pediatric cancer units were prepared to receive rapidly increasing numbers of children with cancer and what the financial implications of such a development could be. It was esti-



**Prof. Hanns Peter Wagner**

mated that first more nurses and lab technicians were needed, but that other services might be affected too, e.g. imaging, blood banking, pathology etc. By developing outpatient clinics, shared care and the collaboration with parent's groups, it was thought that some of these new needs could be met..

In the discussion Ira Soelystro from the Indonesian Childhood Cancer Foundation, presented a poster developed for the International Childhood Cancer Day of January 15, 2002. She underscored the need for a WHO approved List of Warning Signs. Salma Choudhury from the ASHIC Foundation for Childhood Cancer in Dhaka, Bangladesh said, that her foundation uses well baby clinics to advertise early warning signs.

Hanns Peter Wagner explained the concept of local pediatric oncology networks developing around a pediatric oncology unit, with contacts to peripheral practitioners and health care workers to promote triage, rapid referral of good risk patients, palliative care locally for poor risk patients and, where possible, shared care. Many networks of this type have been developed together with parent's organizations, e.g.

NACC: Recife, Brazil, A.Pedrosa, or L'Avenir, Rabat, Marocco, M. El Harras to name just two. The development of palliative care and support for parents of poor risk children in the periphery is very important and alleviates a lot of distress.

Gerlind Bode summarized the discussions by underscoring the important role of parent's organizations in promoting early warning signs but also in developing local pediatric cancer networks.

*Prof. Hanns Peter Wagner*



# SAINT SILUAN\*

## WARNING SIGNS FOR CANCER IN CHILDREN

- S:** Seek: Medical help early for persistent symptoms
- I:** Eye: White spot in the eye, new squint, blindness, bulging eyeball
- L:** Lump: Abdomen and pelvis, head and neck, limbs, testes, glands
- U:** Unexplained: Fever, loss of weight and appetite, pallor, fatigue, easy bruising or bleeding
- A:** Aching: Bones, joints, back, and easy fractures
- N:** Neurological signs: Change in behaviour, balance, gait, and milestones, headache, enlarging head

\*Saint Siluan was a Russian monk who died on Mount Athos in 1938. He prayed ceaselessly for all humanity.

**This list has been compiled by the  
South African Children's Cancer Study Group**

**Children's Cancer Help Line:**

toll-free **0800-333-555**  
(weekdays 08h00 - 16h00)



The warning signs were developed by CHOC, South Africa, and adopted by ICCCPPO and SIOP.

# Hope Floats

## The journey of Rosie Gosling

Cancer was, and is, a physical and powerful emotional scar that will accompany me for the rest of my life. I don't know why it happened, but I am glad that it did, in so many ways.

I was diagnosed with leukaemia in 1996. My treatment was three years long and one of the most difficult things that I have ever had to endure. I think it will be one of the hardest things in my life that I will ever have to go through.

I remember everything because I was 12 when it happened. I remember having chemotherapy and losing my hair. I remember the needles, the doctors, the pain, the tears, the pills, the sacrifices and the heartache. It was a time in my life that helped define who I am. It made me see that I am not invincible or unloved. I am more mature for it and probably now look at life in a different way than most kids my age.

When I first heard about the kayaking trip through the Oncology Department at Children's Hospital, I thought it was a great idea. Kyle Gill, one of the cancer patients, had been working hard to arrange a fun experience involving some of the older cancer kids. He wanted us to be able to get together outside of the hospital, have a positive experience and deal with some of our cancer issues. After pestering the right people, he finally got his wish. Power to Be, a local outdoor adventure company was hired to take six kids from oncology out sea kayaking for 10 days.

**In the past 30 years, the number of childhood cancer diagnoses in our province has doubled.**

When I got accepted to go on the trip, I was thrilled, but a little worried because I knew I wouldn't really know anyone except Sharon, the hospital's social worker. Not that I am a wallflower or anything, but spending 10 days with strangers can be a bit an overwhelming and freaky thing to think about. Despite my reservations, I was so excited about trying sea kayaking for the first time that my concerns seemed to wane the closer our departure day approached. I wanted to do a lot of thinking about my whole life and where I was going. I also wanted to get through a few of my cancer issues. After all, this was the reason that we were going; cancer had brought the six of us together.

When I got to the ferry terminal I met the other kids who were going on the trip, Elsa, Kai, Meagan, Aaron and Brett. I was later told that Kyle couldn't come because he was sick again and had to back to the hospital. I was sad for Kyle, but knew that he'd want us to go out and have a blast, even if he couldn't make it.



The kids that did come were nice. Because we had share the experience of cancer, I felt instantly bonded to them. You know the kind of connection you feel when you're with old friends? That's what it was like.

So, all I had to worry about was whether I could make it through this entire trip. Cancer has a funny way of making you think you can't do some things, like play a whole soccer game or even paddle a kayak for hours at a time.

**20 years ago, 70% of kids diagnosed with cancer died. Now 75% of them live.**

But after the ferry shuddered away from the dock, I knew there was no turning back. I was going on this trip and I was going to overcome this challenge.

That night we stayed in Port Alberni at a small campsite. The girls set up our tent (far away from the boys!) and got ready for bed. We slept well that night, but got up at an ungodly hour! Tim and Andrew, our Power to Be tour guides roused us at 5:30 am to catch our small charter boat (good thing they're both cute!). When our three-hour trip on the rough sea ended, we found ourselves at a small and remote part of Vancouver Island called the Broken Islands.

Our kayaking began that day. It was pretty scary getting into a kayak for the first time, knowing that the only thing between you and about 80 trillion gallons of water was a thin piece of fibreglass. It was a lot harder than I thought, too. The padding was strenuous, especially if you didn't do it properly. Tim explained that one of the best ways to save energy while paddling was to 'push' the paddle on one side as you pulled it through the water on the other side. At first it felt weird, but after a while we got used to it.

Some of the kids wanted to be in the single seat kayak, but I chose one made for two people, so I could chat while I paddled. That day, I shared a kayak with Elsa. We talked about everything. School, music, boys. It was so great to talk to a girl my own age who had been through what I had. We made the hour and a half trek to the island we were camping at. It felt like it was in the middle of nowhere. To me, it was paradise.

B.C.'s Children's Hospital Foundation is raising \$8 million over the next 5 years for a Paediatric Oncology Research endowment.

We spent the rest our trip kayaking around the Broken Islands. I tried to paddle with someone new every day, to learn more about them and their experiences. We also learned about the sea life all around us, Andrew taught me how to use a compass and I learned about what it took to plan a trip of this nature. Every night we had a campfire and took journals each day. Mostly it was for our thoughts, but I was amazed to see after just a few days of paddling how much more confident I was.

I laugh at all the silly things we did and all the stupid sayings that caught during our trip. I still laugh now when I think of all of us hanging out in the tent in the rain (oddly enough, the boys' and girls' tents moved closer and closer together throughout the trip) and we had a blast! We talked about all sorts of stuff and we all became amazing friends.

I want to thank all the people who made this trip possible for the six of us, especially Kyle, who sadly, passed away in the hospital while we were kayaking.

This trip has been one of the greatest things I have ever done. I made some friends for life. It has also given me more courage than I had before. I wear a ring now that I bought in Ucluelet on the trip. It's Celtic and to me, symbolises all of us coming together in a way that can never be broken.

From this trip, I will take with me courage, strength, wisdom, beauty, power and friendship. I will take with me the memory of a lifetime.

Rosie Gosling, 18, is a former cancer patient at B.C.'s Children's Hospital and a bright young poet and writer

For more information about the endowment for the Paediatric Oncology Research please contact Cindi Coleman at 604-875-2444

*Article taken with permission from "Speaking of Children", a magazine of the B.C. Children's Foundation (Fall/Winter 2001)*

Barbara Cardamone

## SOLDATINI SPARATI – SHOT SOLDIERS

available in Italian from MURSIA EDITORI – [www.mursia.com](http://www.mursia.com)

Barbara Cardamone is a mother of a child who has recovered from leukemia. She wrote this book during her child's illness. The book, published in Italy in February 2002, was very successful and sold more than 10,000 copies in 5 months. It is now in its fourth reprint and will most likely be translated into English very soon.

Barbara herself wrote this foreword for our readers:

"I have only a few lines to tell the story of how the magic of words succeeded in destroying the daily anxiety that possessed me and my role as a mother.

My son, in 1998, was diagnosed with acute lymphoblastic leukaemia, and suddenly we fell into an unimaginable despair with no light at the end of the tunnel.

But I rebelled. You must take the disease by the hand and have a friendly walk with it. Smile at chemotherapy, for irony wins over despair. This book is a collection of happiness and sorrow brought together to make my work possible. It was not intended to undo the hardships I have endured. Therapeutic it was, in that it helped to cleanse my soul of those awful thoughts – how can life be so cruel. The emotions, so impalpable, took shape and are in every page where I don't sing the drama, but I dance with it. I wouldn't want to repeat this experience for anything in my life. I walked on ice for two long years and I played the acrobat .... Many times I thought I would slip and fall,



or I wouldn't make it, wishing for what I was before, a mother with no problems at all. As I have written in my book, I am a better mother and a better woman now. It is often only grief that brings change; only evil, that allows us to see the good.

Filippo, my son, is fine now. He thinks he had a problem with weak cells. He doesn't know he won the most difficult battle of his young life. The soldiers shot into his body by syringes killed the most feared of monsters: cancer."

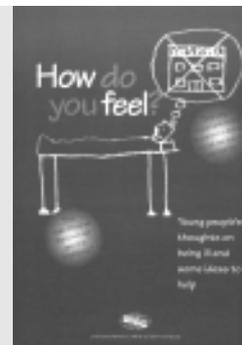
Barbara Cardamone

## How do you feel?

Young people's thoughts on being ill and some ideas to help

A brochure written for young people who have been ill, for their relatives and friends, and for professionals involved in their care, including doctors, nurses and social workers.

To be obtained from  
UICC Education Department  
3 rue du Conseil-Général,  
1205 Geneva, Switzerland  
e-mail: [mortara@uicc.ch](mailto:mortara@uicc.ch)



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