



Hospital-schooling in Jakarta (pg. 10)



INTERNATIONAL CONFEDERATION OF CHILDHOOD CANCER PARENT ORGANIZATIONS

VOLUME 15 No.1 2008



## Message from the Chair

GEOFF THAXTER

The Message from the Chair was written by Geoff prior to his illness. Several months ago, Geoff suffered a brain haemorrhage and was diagnosed with a brain tumour and has not regained full consciousness since then. May we all keep our prayers and thoughts with Geoff and his family in this difficult situation.

Benson Pau, Acting Chair, ICCCPO

Welcome to the latest ICCCPO Newsletter and I hope you like the format. You will see that we are developing continental and regional themes to the layout, as well as continuing with what works well.

Since my last report the board has been active on a number of fronts on plans presented in Mumbai. Many of the board, and past board members, have been involved in developing and organising continental and regional groups and meetings. You will see in this edition the great progress made in the Arab States, Europe, and Africa. We should not under-estimate the value of this work and its benefit to members and the organisation as a whole. As ICCCPO grows in size, continental and regional work has become a central goal and I would like to thank all those involved for their hard work and dedication in making this happen.

The Annual Conference in Berlin is well on track and again there is a huge amount of effort being put into this. This remains the centre-piece for bringing members together annually and is the basis on which so many exchange programmes develop. There is an exciting programme being put together and I would encourage all members to make a special effort to attend, especially if you have not been to a conference previously. The sense of coming together as a family in the world is a feeling you will not lose! Again, my thanks go to the team working on the Conference, both locally and from the board.

On the membership front, we continue to attract new members and support organisations to form. We are currently working with SIOP to identify countries where they have members but we do not, to see how we might work together to help form new support organisations that would benefit the families and patients, as well as support the doctors and nurses in their work.

The work on the World Child Cancer Foundation is progressing well. The board of WCCF is currently selecting the initial two projects to support and expect to announce details during the course of this year. It is important that the initial projects can demonstrate success to help encourage further funding. A further update will be provided in Berlin.

Finally, I wanted to remind you this is your organisation. The board work on plans that are presented to the Annual General Assembly for approval, but we always want to encourage new ideas—especially where ICCCPO can help.

Geoff Thaxter, Chair

## Contents

- 02 GLOBAL REPORT
- 16 CONFERENCES
- 19 SURVIVORS
- 21 NEWS FROM THE BOARD
- 22 MEDICAL NEWS (SIOP)
- 22 ANNUAL MEETING 2008



### COMMEMORATING 7 YEARS OF THE ICCD

12

Read how the Indonesian Childhood Cancer Foundation (ICCF) collaborated with the Indonesian Armed Forces to hold an outdoor bound course...



### SURVIVORS GATHER IN MUSCAT

16

Read a collection of reports from the ICCCPO Conference in Muscat, Oman...

## Contact ICCCPO

ICCCPO Secretariat  
c/o VOKK  
Schouwstede 2B  
3431 JB Nieuwegein  
NETHERLANDS

Produced by CLIC Sargent  
(United Kingdom)  
www.clicsargent.org.uk

# Global Report

## EUROPE

### Italy celebrates the 6th Day of the Worldwide Fight against Childhood Cancer

On 15th February, in Rome, the Confederation of Italian Parents of Children with Cancer (FIAGOP) celebrated International Childhood Cancer Day (ICCDay) with a conference for the public and press. The conference introduced a project to implement a network of certified data, called "L'Amore Cura" (Love Cures), promoted and shared in close collaboration with the doctors of the Italian Paediatric Haematology and Oncology Group (AIEOP).

This is the first time that both doctors and families have collaborated on a common project in Italy.

#### How this venture began

The Internet has radically influenced research methods, favoring a cooperative approach among research institutes, and optimising the time and costs of the complex procedures of multicentric clinical trials. The goal of this project is to make full use of the Internet's potential, in order to provide a more effective instrument for the research on paediatric haematology and oncology diseases.

In 1985 the AIEOP initiated a collaboration with the non-profit Consortium CINECA, to develop an IT model for gathering, managing, monitoring and analysing information and the relative flow of the protocols of the research group. This model allows people to use the system without the need for minimal technological equipment. All they need is a computer with Internet access.

The database gathers all the information relating to each patient. Personal data, diagnoses, therapies, protocols used, follow-up information and unfavorable events are available online through a simple and well-explained system of Remote Data Entry. Such information is protected, so a username and password must be used to enter the AIEOP web portal. The portal is composed of a public area with information about the Association, its research activities, its centres

and its projects, as well as an area reserved for its researchers, coordinators, members, etc.

Ultimately, "L'Amore Cura" intends to promote a pilot project of telemedicine, to improve the treatment of patients who are far away, even in underdeveloped geographic areas.

The FIAGOP, aware not only of the medical importance, but also of the social importance of the project, committed itself to economic support, through a campaign of text messages of solidarity that has involved many telephone companies, as well as the world of communication, through the radio, newspapers and various television programs. During the week of 9th – 17th February they continually spoke about the project, making the public more aware of the problems involved in paediatric oncology.

On 15th February, "L'Amore Cura" was introduced to the public at a conference hosted by the Guardia di Finanza (The Italian State Financial Police) in its main reception hall.

In Italy the Guardia di Finanza is a Government police corps, particularly admired, that specialises in controlling tax evasion, organized crime and drug traffic. Its authoritative support of our project has been a guarantee of great transparency and the absolute seriousness of our fundraising activities.

- 03 MORE RESEARCH NEEDED ON PAEDIATRIC ONCOLOGY TRIAL PARTICIPATION
- 04 TWINNING ACROSS THE ADRIATIC SEA
- 06 CHIMAERIC T-CELLS FOR THE TREATMENT OF PAEDIATRIC CANCERS
- 07 FIGHTING CANCER WITH POETRY IN BOSNIA

Continues on page 3...

# Global Report

## EUROPE

Continued from page 2...

Our audience included the most authoritative representatives of the AIEOP, representatives of parents from many of the Italian regions, representatives of the Italian Institutions, and even delegations from Morocco and the Ukraine. We were also delighted to welcome the wife of the present President of Italy, Mrs. Clio Napolitano; the wife of the former President, Mrs. Franca Ciampi; the new President of the SIOP, Dr. Maarten Egeler; and our ICCCPPO President Geoff Thaxter.

The total sum raised during 9th – 17th February 9th was almost €100,000, which will cover the first phase of the project. We are very proud of this result, and also of the pact now sealed between doctors, families and institutions.

With great generosity “le Fiamme Gialle” (the Yellow Flames—the nickname for the officers of the Guardia di Finanza) provided us with all the financial assistance necessary to facilitate our project. They also wanted

to visit, together with representatives from the local associations, the children in all the oncological and haematological wards in the various Italian centres, bringing gifts and creating moments of animated conversation and emotional involvement.

This helped the people and children involved to see the Guardia di Finanza in a new light. Instead of a severe and repressive group, they are warm-hearted men. Their visit to the wards also represented a moment of promotion and visibility for the small associations of local parents, realising a third objective of the ICC Day.

We have created a solidarity network to promote a database that could improve the treatment of Italian children, and also, hopefully soon, that of children in developing countries. There could not have been a better way to celebrate International Childhood Cancer Day. •

## More research needed on paediatric oncology trial participation

**More teenagers and young adults need to be recruited for clinical trials of new cancer treatments, to improve drug development for these vulnerable groups, according to the April issue of *The Lancet Oncology*.**

“Clinical trials lie behind remarkable scientific progress in the treatment of childhood cancer”, explains Kathy Pritchard-Jones, from the UK Institute of Cancer Research. “Current survival of acute lymphoblastic leukaemia is associated with a 35-year series of trials during which 10-year survival increased from less than 10% to 80%.”

Phase III clinical trials need large numbers of patients to provide evidence of efficacy and safety. However, different age groups often respond to treatments in different ways, so

findings from adult trials cannot be directly applied to children and younger people.

Just starting trials in rare cancers can improve survival. After the International Society of Paediatric Oncology’s trials of treatment for hepatoblastoma, a very rare liver tumour, survival increased from below 40% to around 60%.

Although more than 70% of eligible children with cancer are recruited into phase III trials in Europe and the USA, recruitment numbers



The idea of randomisation in a clinical trial can be challenging for families of a child newly diagnosed with cancer

Continues on page 4...

# Global Report

## EUROPE

Continued from page 3...

vary between different age groups. While participation among children under 15 might exceed 70%, less than 15% of 15 to 19-year-old patients, and as few as 2% of patients aged 20 to 30, are recruited into clinical trials. This may be because they fall into the gap between paediatric and adult oncology specialists.

Low numbers of trial participants means evidence to support treatment changes is often poor. To improve this we need a coalition of forces, including funders, policy makers, biologists, clinicians, and patients. •

**Prof Kathy Pritchard-Jones**, The Institute of Cancer Research and Royal Marsden NHS Foundation Trust  
**Dr Jeremy S Whelan**, Department of Oncology, University College London

## Twining across the Adriatic Sea

The Italian Peninsula and the countries of “former Yugoslavia” are separated by geographic chance. The connections between our countries are many, and ideas fly back and forth. Doctors share their expertise, and the doctors on the eastern side of the Adriatic have become very accomplished, although hospitals and clinics are few and poorly supported. Many children still come to Italy to be cured, usually supported by non-profit organisations such as AGEOP-RICERCA, an Italian parent organisation based in Bologna.

NURDOR is based in Serbia and is an umbrella organisation uniting five hospital-based parent associations. Cancer children are a low priority in this post-war country, and social and psychological assistance is still very poor, almost non-existent.

We often wonder how valuable our ICCPO meetings are. Well, at these meetings, during coffee breaks, representatives from Italy and Serbia formed a friendship and gave birth to this unusual form of twinning.

AGEOP-RICERCA was interested in participating in a twinning program. The representative of NURDOR was desperate—there was so much to be done, but the parents involved in the Serbian associations had little time or energy to dedicate to association work.

AGEOP has agreed to set up and maintain an office, with a full-time secretary, for NURDOR. NURDOR has the know-how for what has to be done, but not the personal strength. The office will facilitate this work, as well as providing a meeting place for parents’ self-help reunions.

For AGEOP, helping NURDOR means we can help many parent organisations, families and children. We are donating, not so much money, as time and energy to these parents, so they can organise and set up programs to better the care of cancer children in Serbia.

We thank ICCPO for getting us together, and providing the stimulus and expertise for building this bridge across the Adriatic Sea. •

**Slobodanka Eric**, President NURDOR, Belgrade, Serbia  
**Suzanne Cappello**, President AGEOP-RICERCA, Bologna, Italy



Signing ceremony with NURDOR

# Global Report

## EUROPE

### Chimaeric T-cells for the treatment of paediatric cancers

**Leukaemias are the most common childhood cancers, while malignant lymphomas—including non-Hodgkin lymphomas—are in third position after brain tumours. Many children with leukaemia/lymphomas still fail current therapies.**

The CHILDSHOPE project links a network of EU-based partners with a broad experience in paediatric haematology and oncology, immunology and cell & gene therapies. Using recent advances in genetic engineering, the project aims to develop a safe and highly-effective adoptive immunotherapy, with little toxicity, for children with advanced or refractory malignancies.

#### T-cells

T-cells are immune cells that recognise and kill virally infected cells, but they often lack the correct T-cell receptor (TCR) to recognise targets (antigens) on tumour cells, so they fail to kill cancer cells.

We can now remove T-cells from a patient's blood and add a tumour-specific receptor.

Raphael Rousseau, CHILDSHOPE coordinator  
Marguerite Stam (ICCCPO)

Once administered back to the patient, these re-programmed T-cells will recognise and kill cancer cells.

The CHILDSHOPE project is the first comprehensive attempt to administer anti-tumour chimaeric T-cells to children with haematopoietic malignancies. We believe this will not only kill target cells but also contribute to the release of yet unknown tumour-associated antigens (TAAs).

*This is a new approach in paediatric cancer treatment since it brings from bench to bedside (and back) an innovative technology as yet never applied in children with advanced or refractory haematopoietic malignancies.* •

### Fighting cancer with poetry in Bosnia

**Our thanks to everyone who is in contact with Irina Ban from Belgrade. What is new about our association is that we are promoting my first book of poetry, called "FOR ALL". I wrote these lyrics to help my daughter, who fell ill with leukaemia before she was 8 years old. The proceeds will go to the PIPOL association in Tuzla, Bosnia, so all the members and I are trying to sell copies to help children from my region of Tuzla, who are now ill with leukaemia and cancer.**

My name is Enisa Milinovic and I was born in Tuzla in 1967. PIPOL is a young organisation but we are good parents and we work as a team. We meet in my two-room apartment because the government and humanitarian organisations don't want to help us, so I must tell you that I am little bit tired of it all.

I have tried to translate the song that I have written for my daughter Ema and for all the Emas in the world. Ema is now 16 and studying medicine in Tuzla. She is a good person and I hope she will be a good doctor when she qualifies.

 •

#### GRRR, GRRR, HORRIBLE LIONS

When a malady  
Consumes you all  
When it overpowers  
Your body and soul  
Don't give it your fists  
Don't give it your play  
Nor your laughter.

Move your finger a bit  
Move your entire arm  
Touch the Sunshine  
And the tiny flowers in the meadow  
And the butterfly  
That parades in the straw.

For illness is weak  
A hungry little coward  
So what if it's 300 kilos  
We are strong, too  
Although we're small  
We are horrible, hungry lions  
for her.

Enisa Milinovi

## An inspiring conference on childhood cancer

The CHOC Childhood Cancer Foundation of South Africa held its 2008 conference in Johannesburg on 12th and 13th April.

After a brief introduction and welcome, the opening session began with a talk on 'Why CHOC exists' by Sadie Cutland, a nurse whose daughter is an aplastic anaemia survivor. This was followed by a talk on parental cancer refusal from Professor Mariana Kruger, head of the Paediatric Oncology unit in Pretoria. Reasons for refusal can include fear of stigmatisation and disbelief in the disease's existence.

Samantha Galliet, a breast cancer survivor, then spoke about patient advocacy: the need for patients to learn how to take control of their lives and speak up, even when they feel overwhelmed.

### Session 2: medical and related aspects of childhood cancer

The second session began with a talk on paediatric oncology in the developing world, by Dr Gita Naidu from Chris Hani Baragwanath Hospital. Dr Christina Stefan, from Tygerberg Hospital, then discussed the needs of adolescents with cancer. Although it is more than twice as common as cancer in children it receives less attention in South Africa.

Deborah Jackson, a private dietician, spoke about nutrition for paediatric oncology patients, and its importance in reversing poor nutritional status, malnutrition, cachexia and associated complications.

Edith Ngang, a nurse from Cameroon, talked about the role of traditional healers and how their involvement can have a major impact on the successful treatment of Burkitt's Lymphoma. Two survivors then discussed their personal encounters with traditional Bantu healing techniques.

The session closed with a talk on ototoxicity in oncology by Carina Tudhope. Some drugs can damage the inner ear, causing hearing loss or dizziness, which can affect children socially and academically.

### Session 3: support systems

After lunch, Dereck Jackson spoke about 'discipline without anger or tears'. He explained that there are three stages of discipline: defining the boundaries, giving effective commands and taking action. Hanneljie Opperman then suggested creative ways to stimulate a child in isolation. Her presentation focused on how to help and motivate young patients who are not allowed to see their siblings.

Madge Rix and Anne-Marie Lydall discussed ways of helping bereaved parents through the grieving process. This was followed by 'a conversation on caring' between Dr Zubeida Dangor and Alta Bence, who want to raise awareness about the challenges facing care givers in paediatric oncology.

### Session 4: coping with childhood cancer

Later in the afternoon, Professor John Spinetta of San Diego University talked about adjustment and resilience in children with cancer and their families, focusing on the psychosocial aspects of care.

### Session 5: experiences with childhood cancer

Bronwyn Kemp, a 12-year-old from Durban, opened the second day of the conference with the story of her cancer journey and experiences as a patient. Mamorena Seleke and Olivia Mhlanga then talked about siblings' and friends' reactions to childhood cancer. They provided advice and alternatives to consider when working with cancer kids.

Continues on page 7...

# Global Report

## AFRICA

Continued from page 6...

Next, a talk on the later effects of childhood cancer by Dr Linda Wainwright. Almost 80% of children and adolescents now survive cancer, but therapy may cause damage later on in life.

Carin Marcus then discussed ‘the silent grief’—bereavement in childhood—and how children struggle to integrate loss into their lives and find constructive ways of moving forward. Brenda Herbert spoke about Talking Mats™, a simple communication method that helps children express themselves in an effective, non-threatening way.

### **Session 6: childhood cancer in Africa**

The final session was opened by Dr Jane Poole from SIOP. She talked about problems in Africa and how to help local caregivers build adequate infrastructure for local delivery of cancer care. She was followed by Professor Peter Hesselting, who discussed the CHOC Parent Support Programme at Banson Baptist Hospital, Cameroon.

The final talk was given by Geoff Thaxter of ICCCPPO, who outlined the benefits of international twinning programmes. He discussed the key factors for success and touched on ICCCPPO’s new initiative, the World Child Cancer Foundation. •

# Global Report

## ASIA

### Listening to each other—a story for parents

**18 years ago, when he was 4, our youngest son was diagnosed with Non-Hodgkin lymphoma. Today he's a healthy survivor with a job, lots of friends and a girlfriend.**

Vividly I remember my first steps in the hospital. I could only look at the other children. They were very sick. But one little guy was racing around on a scooter, a bag of liquid attached to his arm and his father running behind. Or that girl. She knew she was going to die, but asked me to help with her homework. Then I couldn't understand. Now, after listening to so many parents and children, I do. We all need hope.

#### Parents listening to, with and about each other

First of all, parents of a child with cancer have to listen to themselves. Intuition is more powerful and important than many will admit.

Nurses and doctors can encourage parents to listen to their own feelings. Parents confronted with a child with cancer can lose control. Listening to themselves gives them the power they need.

#### Listening to the child with cancer

This is one of the most difficult things. The threat of losing your child blurs your vision. Parents want to protect and spoil their child. Listening to a child's real needs can help parents to be parents again.

I remember when I was with my child on the oncology ward. I sat beside his bed. I endlessly read him books about a little gnome, I tickled his back when he was restless from the chemotherapy and when he couldn't sleep from the pain we took a bath together.

I tried to read his mind. What was going on in his little head? That he understood the

seriousness of his illness was evident. "Do you think I'll ever see the beach again?" was one of his first questions.

#### Listening to siblings

Besides being afraid and careful, siblings of children with cancer can be angry and jealous, lonely and left out.

A year after the start of the treatment of my youngest, his brother was lying in bed with toothache. He was very happy and smiled the whole day. It was him getting attention, at last!

Professionals can help parents by knowing the names of the siblings, by asking after them, by stimulating parents to talk to them and spare some special time with them, by inviting them to the ward.

#### Parents listening to each other

'I was in the hospital with my daughter; my husband was at home with the other children. Although we phoned regularly, I missed his arms around me. Once at home, I thought it would be better. But I was exhausted. My daughter with cancer, the other children, my work, it was all too much.' The little girl survived, but this couple had to start again.

Staying close as partners when you have a child with cancer is not easy. From the moment of diagnosis 'normal' life ceases.

Professionals can stimulate parents to spend time together. Ask them what support they have. Is their network strong enough? Do they need extra help? If they are divorced, are they still able to communicate?

- 09 SUPPORTING CHILDREN WITH CANCER IN SYRIA
- 10 HOSPITAL SCHOOLING MAKES A DIFFERENCE TO KIDS WITH CANCER
- 11 SAHAYTA NEWS
- 12 GRANT A WISH DAY – SATURDAY, 3RD MAY 2008
- 12 INDONESIAN CHILDHOOD CANCER FOUNDATION CELEBRATES THE 7TH ANNIVERSARY OF THE INTERNATIONAL CHILDREN'S CANCER DAY

“ My daughter with cancer, the other children, my work, it was all too much. ”

Continues on page 9...

# Global Report

ASIA

Continued from page 8...

## Parents listening to doctors and nurses

Parents become cancer experts. Suddenly they use words like blood counts, leucopenia and bone marrow. The more they become attached, the greater the distance from the normal world.

'I felt I was living in two worlds' says one mother. 'On the one hand the world of cancer, on the other hand the world of school, shopping, laundry, etc. I sometimes felt safer in the hospital than at home.'

Are parents listening to doctors and nurses? Sometimes the bond between them is very close. But the relationship is unequal. Is it safe for parents to ask questions? Can they be critical? Of course, parents can be very annoying. But they are also vulnerable,

anxious and tired. Encourage them to ask questions and talk about their feelings.

## Parents meeting parents

It's comforting to hear that your feelings are normal. Parents can share experiences and learn from each other. How do you get along with a child with cancer? What about the other children? Is it normal to be afraid of the future? Is it normal to feel depressed?

## In the end...

- Parents need time to heal, to find confidence again.
- Every child and every parent is unique.
- Listen with your ears and your eyes!
- Empower parents by stimulating them to listen to themselves. •

## Supporting children with cancer in Syria

**BASMA (BAttling to SMile Again), is a nationwide volunteer-powered NGO supporting children with cancer and their families in Syria.**

Our objectives:

1. To provide moral, psychological, and educational support to children with cancer in Syria during treatment.
2. To provide financial and psychosocial support services to families of children with cancer.
3. To provide medical services and supplies otherwise not available, as well as specialised medical staff, in the children's cancer units in Syria.
4. To raise awareness among families of children with cancer and the community about the disease; and mobilise the community to support this cause.
5. To build up cooperation with regional and international children's cancer centres and any other related governmental and non-governmental parties locally, regionally, and internationally.

BASMA members regularly visit children in the cancer units in Syria. These visits include a variety of activities and entertainment programs for the children.

We also strive to stay in touch with children while they are at home between hospital

visits. We invite them to participate in organised activities, and contact parents to make sure their child is doing well.

BASMA runs a financial support program, which is divided into an accommodation program and a medicine support program.

Continues on page 10...



# Global Report

## ASIA

Continued from page 9...

This helps to provide parents with medicines that are not readily available from the hospitals in Damascus.

BASMA also covers a percentage of the treatment cost of some of the children being treated in specialised centres outside Syria. All these cases are followed up and supported socially by the BASMA team during and after the treatment period.

Our family awareness and community awareness programs help to raise awareness about childhood cancer.

Finally, BASMA supports medical units that treat children with cancer, in order to provide

better quality services and comfort to children during their hospitalisation. BASMA employs and trains staff, and provides equipment and food.

To carry out all this work, BASMA relies on a dedicated team of 80 volunteers and 4 employees. We also rely on the invaluable support received from the community, and from generous individual and corporate donors inside and outside Syria. Without this vital support, we would not be able to continuously upgrade and maintain the quality of the services provided to children with cancer and their families. •

Mayya Assaad, Founder and Chair of BASMA, Damascus, Syria

## Hospital schooling makes a difference to kids with cancer

**Children with cancer have to spend most of their days in hospital. They are deprived of the chance to seize the day as their days are often already seized by their conditions.**

Now, in Jakarta, a hospital-schooling program, SEKOLAH-KU (my school), is giving them another chance.

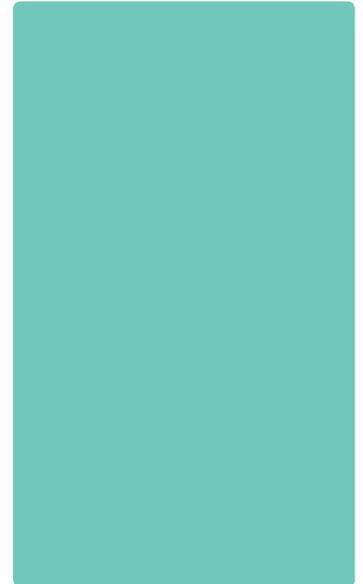
“I wish the activities were held here every day,” says Susi, mother of cancer patient Farhan. Farhan, 5, is arranging a picture puzzle with a tutor from SEKOLAH-KU, which is run by the Indonesian Care for Cancer Kids Foundation (YKAKI).

“He used to cry whenever he got fever and could not go to school. It’s a good thing they bring the activities here. It keeps Farhan from feeling bored in bed,” says Susi, whose husband works as a street vendor.

The tutor coordinator, Friesda, a student majoring in education, says, “We lend books to children who want to read. Sometimes they are returned, sometimes they aren’t. It’s no big deal.”

Children are not always able to do the hospital-schooling activities.

Sonia, 11, was lying weakly on her bed when one of the SEKOLAH-KU tutors visited her. Sonia’s mother sat beside her, telling the tutor Sonia could not join the schooling that day. “She is always eager to participate in SEKOLAH-KU. She likes to study. But today she is so weak after having her treatment.”



Continues on page 11...

# Global Report

## ASIA

Continued from page 10...

Ira Soelistyo, one of the founders of YKAKI, says the type of activity held at the hospital ward depends on the mood and physical condition of each child. "We cannot force them, especially when they feel weak after chemotherapy."

According to Ira, "Many children with cancer are absent from formal schooling between

five months and two years. Unfortunately, some schools disallow students who have been absent from classes for more than 30 days from taking exams. We want to facilitate these children's education because it is their right. We have adopted this concept of SEKOLAH-KU from the developed countries and we implement it according to our situation and condition." •

Agnes Winarti, The Jakarta Post, Indonesia  
Ira Soelistyo, ICCPO Executive Committee Member

“ Many children with cancer are absent from formal schooling between five months and two years. ”

## Sahayta news

The following events have taken place in the Advanced Paediatric Centre of P.G.I under Sahayta Bal cancer Sahyog:

### Parent Group meeting, 2007

The meeting was organised to facilitate interaction between parents, doctors and Sahayta volunteers. A number of problems were discussed, including parents' apprehension about relapses, and the physical and emotional trauma associated with the disease which affects both parents and siblings. Some parents broke down, opened up and gained strength from others around them. Children with cancer presented an impromptu entertainment. Some danced, some sang and some recited poems.

### Celebrating festivals in 2007

Rakhi, Diwali and Christmas were celebrated in the hospital, and gifts and refreshments were distributed.

### Painting competition 2008

As a part of the celebrations of ICCD, a painting competition was organized, and large numbers of children participated. The kids won prizes and were absolutely thrilled.

### ICCD Function, February 2008

19 Children varying from age 3 to 16 participated in a dance medley, an amazing sequence based on the latest musical hits.

### Cash awards in 2007

Cash awards of Rs. 5000/- each were given to 7 children. The parents were asked to deposit the money in the bank for their child's future use.

### Treatment in 2007-8

Sahayta Bal Sahyog sponsored the treatment of 40 children and spent nearly 6 Lakhs on chemotherapy drugs.

### Nutrition programme

A nutrition programme was started in Feb 2008 to provide protein supplements to children undergoing treatment.

### Toys and games

Toys, storybooks, indoor games, drawing material etc are being provided to hospitalised children on a regular basis. •



# Global Report

## ASIA

### Grant a wish day – Saturday, 3rd May 2008

Childhood oncology patients struggle with their disease on a day-to-day basis. The pain, nausea and discomfort are part of their lives for the duration of the treatment. While every effort is made to ensure that they receive the complete protocol the doctor prescribes, often the small ingredients that make childhood are forgotten. The fun, the games, the gifts become secondary.

Every child has a wish, but the desires of a childhood cancer patient are pushed to the background. Recognising this, Cancer Patients Aid Association worked with the Sadhu Vaswani Trust to fulfill some patients' wishes.

On Saturday 3rd May, the children were first entertained by a magician, then invited to sing along with Kiran, a talented young

singer. Snacks followed. Then the grand finale—each child was presented with the gift they had requested. Each gift was wrapped and addressed to the individual child. Immense efforts had gone into ensuring that there were no mistakes.

From video games to dolls to cricket sets and cycles—the children were delighted and, for an afternoon, childhood returned. •

Shubha Maudgal, Cancer Patients Aid Association, Mumbai, India



### Indonesian Childhood Cancer Foundation celebrates the 7th anniversary of the International Children's Cancer Day

Children with cancer are ready to build a strong nation.

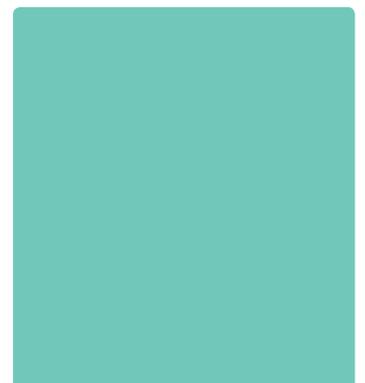
To commemorate the 7th Anniversary of the International Childhood Cancer Day, the Indonesian Childhood Cancer Foundation (ICCF) collaborated with the Indonesian Armed Forces and held an outward bound course at their Military Training Base in Bandung, a cool place outside Jakarta.

There were about 120 participants, aged between 7 and 16, and several survivors from various parts of Indonesia. The children started the day with light aerobics, then walked around the area singing patriotic songs. After breakfast they were taken to

the field to be trained by special trainers. Activities included crossing over a bamboo trunk, crossing over a moving bridge to practice stability, and rock climbing. The most challenging activity was the 'flying-fox'.

On the last day of the outward bound course all participants—not just the children with cancer, but their parents, doctors, nurses and board members of the Foundation—planted about 200 trees, to participate in the GO GREEN Campaign and show that we are concerned about global warming, too. •

Lastri Krisnarto, Indonesian Childhood Cancer Foundation



# Global Report

ASIA

## Help Filipino kids fight for their lives

Here is an example of how our friends in the Philippines are galvanising support for Childhood Cancer Month in their country.

Dear People,

Hi! April is Childhood Cancer Month in the Philippine Health Calendar. Here are some facts about childhood cancer and how you can help Filipino kids FIGHT for their lives!

**FACT 1:** Childhood Cancer can be cured!

**FACT 2:** Every 3 hours A Filipino child dies of cancer. 8 every day. 2,500 in a year. BECAUSE THEY ARE POOR!

**FACT 3:** YOU CAN STOP THE DYING!

### Did you know that 5 out of 10 children with cancer have leukaemia?

Their treatment requires 2-3 years of chemotherapy sessions, costing an average of Php200-300,000. Cancer Warriors Foundation, Inc. (CWF) provides direct treatment and assistance to kids with cancer and helps them gain access to more affordable medicines. For only Php5,000-8,000 a month, you can ensure that a child with cancer will get the treatment they need to survive. Here are ways you can help:

#### Sponsor-a-child program

ADOPT a Kid With Cancer (KWC). Be a monthly sponsor or pool your resources with your classmates, friends, officemates, church or organisation. A donation of Php5,000 will cover the full cost of one month's chemotherapy.

Get your barkada involved! If your barkada is composed of 10 people, each person can donate Php500 a month or just Php17 a day.

Or do you have a cell group in church? If you have 15 members in a cell group, each person can donate Php333 a month or only Php11 per day.

You can also gather up your colleagues or workmates. If you have 20 people in your department or organisation willing to share in CWFI's vision, each person can donate Php250 a month. That is only Php8.50 per day!

#### Be a treatment partner of kids with cancer

A monthly pledge/donation of Php1,200 will help buy the required monthly oral medication for one child.

#### Help a kid with cancer

Donate Php500 and help buy one chemotherapy vial for one child.

#### How much do you value a child?

Cancer Warriors Foundation believes that every KWC must be given the opportunity to FIGHT for his or her life and have a future beyond cancer. WE CAN and WE MUST help kids beat cancer. ONE DEATH IS TOO MANY. HELP US STOP THE DYING! No kid, no family should have to go through the devastating journey alone. Be there for them.

Let's work together in saving lives, building better futures and keeping hope alive. BE A PARTNER OF HOPE. Give KWCs the most precious gift of all—a chance to LIVE!

KONTING SAKRIPISYO! MARAMING MAGBEBENIPISYO! Maraming salamat po sa suporta! God bless!

James A •

# Global Report

## NORTH AMERICA

### Listening ... to, with and about each other

**The diagnosis of cancer creates enormous emotional turmoil, especially when the person receiving the diagnosis is your child. Such a diagnosis introduces significant emotional 'noise' into the dynamic between caregivers, patient and family, and increases the communication challenge.**

It is at just this crucial, tumultuous time that the partnership between the medical team and the family is established. Both family and medical practitioner are thrust into this partnership and it is of the utmost importance that a relationship be established that is based not only on excellent medical care, but on open communication, trust and mutual caring.

In the paediatric oncology world there isn't the advantage of a prior relationship. Soon after the diagnosis is made a very specific and special relationship needs to be fostered. We embark on a journey together, a journey that, as a treating physician, I find is always unique and always a privilege to be part of. It becomes an intimate relationship where you truly see families at their weakest and their strongest.

Family dynamics are challenged and the care experience of the family and patient is deeply impacted by the trust relationship that is established. The diagnosis of childhood cancer has enormous ramifications. One child's illness can impact the nuclear family, the extended family, the child's social network, soccer teams, school, scouts and religious communities. Up to as many as 600 people's lives can be touched by the diagnosis of one child.

In the multidirectional caregiver partnership the ability of parties to listen to one another effectively and to truly hear one another is influenced by numerous factors and frequently undermined by divergent individual foci. The result is often miscommunication.

Our interactions are influenced by our personal and culturally different perspectives—the many basic differences that make us who we are. If we do not overcome these different perspectives, walls can be built up within this relationship and may become insurmountable.

We all come from different perspectives—with similar goals but different foci: the physician focusing on diagnosis, treatment, outcomes and medical delivery. The family, coloured by emotional turmoil, is focused on care, hope and cure. Initially the family may be numb and when one speaks they may not hear. Information needs to be repeated, reinforced. In this situation, how the news is delivered is much more important than what is said.

The fundamental building blocks are trust and the ability to listen to each other. During this journey we each listen to different things. It is important to remember this is about sharing information: not only are we giving information but we are receiving information in return.

We are all intellectually, emotionally and culturally influenced by that information and as we deliver the information, as care providers we need to truly know ourselves and acknowledge that we do not come to the relationship value-free. We need to understand our own biases and value systems, so that our own perspectives do not become a source of conflict in the relationship with families.

Continues on page 15...

# Global Report

## NORTH AMERICA

Continued from page 14...

To enrich the care giving experience and empower the team, communication is vital; not only so that all parties can share their needs and hopes for the future, but also so that fears are explored too and not just swept under the carpet.

We are all human and being human means being real. Conflict is inevitable; but rather than finding fault, we need to take time to find the remedy, take time to step back and listen and try to understand our different perspectives. In this way hopefully we will be able to journey on, acknowledging that we will always have these different perspectives.

In summary, the relationship that the care provider has with the families is a journey

that starts when we are forced together; this can be a very rich journey, unique in every way. As we experience personal growth, we recognise our own needs, not ignoring conflict but cultivating skills to empower us.

Relationship building is what makes being in paediatric oncology so special. It takes time and this is often a challenge in busy clinics when time is not always a privilege granted us. We need to listen to each other, not just to the words but to the feelings that they convey, and sometimes conceal. The foundation of these relationships is one of trust and being human. As Viktor Frankl so eloquently wrote, “being human means being conscious and being responsible.” •

Caron Strahlendorf, Associate Professor, Division of Haematology/  
Oncology/Bone Marrow Transplant, BC Children's Hospital,  
British Columbia, Canada

# Conferences

## REPORTS FROM THE ICCCPO WORKSHOP IN MUSCAT, OMAN

### Parent/Survivor Workshop

The ICCCPO 2008 Asia Parent/Survivor Workshop was held in Sultan Qaboos University, Muscat, Oman on 27th February 2008.

ICCCPO is ambitious to link and nurture parent support groups in the Arab world, to share knowledge and experience, and improve access to the best possible care for children with cancer all over the world.

The workshop attracted more than 80 participants, far more than expected. Among the participants were childhood cancer parent and support groups from Egypt, Hong Kong, Lebanon, Morocco, Oman, and Syria. Thanks to the support of Sultan Qaboos University Hospital and The Royal Hospital, many local families and medical staff were able to join the workshop, as well as paediatric oncologists from the Middle East Childhood Cancer Alliance.

The workshop was sponsored by Mrs. Zuwaina Al-Mahrooqi, wife of H.E. Dr. Mohamed Al-Romhy, Minister of Oil & Gas in Oman. Mrs. Zuwaina gave an emotional opening speech, touching on her own early experience and fight against cancer.

The sharing session was initiated by local medical professionals, followed by the National Cancer Association of Awareness (the only NGO in Oman) and local families. After a tea break, visiting parent and support groups shared information about activities in their own countries. The afternoon workshop discussed parent support group development in each participating group or country. •

Benson Pau, Co-Organiser of ICCCPO 2008 Asia Parent/Survivor Workshop

### The importance of mutual support for parents

**6 years ago, the mere thought of attending a conference for parents of children with cancer, or being part of a team or event that was related to childhood cancer, would have been a terrible nightmare for me.**

After 6 years of childhood cancer experience, in fact the 2 different cancers of my 6-year-old son Garen, I was in Muscat, at the ICCCPO conference, proudly introducing, along with Mrs. Christian Makarem, the Children's Cancer Centre of Lebanon, a centre without whose doctors, staff, and volunteers, it wouldn't have been possible for me to stand there in Muscat, to tell everyone "my son is doing well"...

Cancer is not something a parent wants in their child's record book. You want to record height, weight, first tooth, first smile, first step. Not cancer, first chemo, first radiation session. Not LPs or bone marrow tests.

When your child is diagnosed with cancer, your world falls apart. You feel life has ended for you, and involuntarily you set off on a long and painful journey, when all you care for and live for are chemotherapy sessions,

- 18 A DREAM COMES TRUE
- 18 HOW I BENEFITED FROM THE ICCCPO ASIA PARENT/SURVIVOR WORKSHOP



Continues on page 17...

# Conferences

## REPORTS FROM THE ICCCPO WORKSHOP IN MUSCAT, OMAN

Continued from page 16...

blood tests and transfusions, surgery, immunity levels.

The hospital becomes your life, your reality and all that really counts.

Then you realise you need support. Support to go on because life goes on. Support to take care of yourself and your health. Support to function as a family, to take care of your other children.

That support can only be provided by people LIKE YOU. Mums and dads who have gone or are still going through your experience. With all the empathic and sincere understanding of family, friends, nurses and doctors, the most realistic support comes from someone who is, like you, the parent of a child with cancer... a person who has learned, like you, that this life holds no guarantees.

At the conference there were parents of children with cancer sharing their stories of battles fought and won, of battles fought and lost, of battles still going on. There were cancer survivors, appearing so energetic, hopeful, full of life. Their attitudes were contagious.

And yet, there were other parents with whom we shared a special outlook on life: real life for us takes place under the cancer umbrella.

Sharing the experience of childhood cancer and learning from it formed an emotional bond between the parents present at the conference. Everyone believed in the need to

support parents of children with cancer—to help them overcome the obstacles created by cancer itself, to overcome the feelings of shock, disbelief and denial, fear and anxiety, guilt, sadness, depression, anger.

We learned as parents that we need to seek comfort from one another by talking about our feelings, to discuss fear and anxiety and seek reassurance from each other, to learn strategies to reduce anxiety or tension, to hear how other patients and parents have coped, to take as much control as possible of everyday events and decisions, and to talk with other parents whose children have similar diagnoses, yet different backgrounds and experiences.

I came back from the ICCCPO Conference with a more positive attitude, with more hope, and a more committed and responsible perseverance, convinced that parents of children with cancer should unite, meet, share and support each other.

We need to stay on-task, taking care of our children, without surrendering to hopelessness, without feeling fear and anxiety, without constant apprehension about the future.

As the mother of a child who has gone through the painful experience of two different cancers, but who goes on fighting with the strong will to win, I believe the best way to beat cancer is to live fully in the present. As for the future, I believe God will take care of it. •

Shaghig Hudaverdian, mother of Garen, Beirut, Lebanon

# Conferences

## REPORTS FROM THE ICCCPO WORKSHOP IN MUSCAT, OMAN

### A dream comes true

**I've often dreamt of getting on a plane and travelling to see the world from the sky. And when my dream finally came true, it was to attend the ICCCPO Parent Support Group workshop in Muscat. I was meant to be one of the speakers to tell the audience about my experience as a mother of a child with cancer, my boy Majdi who has Osteosarcoma.**

Meeting all of you in Oman, this hospitable country, gave my shattered soul trust. I felt a great communication between the workshop participants, which made my pain easier to bear, my eagerness stronger and my nerves tougher. Even my tears were gone because I felt like we are one family brought together by the same calamity.

I dream of a world where everyone helps each other. By attending the workshop, I realised that this exists in the ICCCPO family.

Souad AlAtwan, mother of the child Majdi Bechara, Damascus, Syria

I believe that with God's will, science's capabilities and the efforts of kind-hearted people, a cure will be found for all diseases, especially when people join forces to save another human life.

I invite you to hold your next conference in my beloved Syria, the country of BASMA Association to Support Children with Cancer and their Families. •



### How I benefited from the ICCCPO Asia Parent/Survivor Workshop

**I am a cancer survivor and Founder and Chair of the National Association for Cancer Awareness, the only cancer NGO in Oman. We work closely with the Government and the University Hospital to bring awareness and education about this disease, support the patients and their families, and support research at the Sultan Qaboos University.**

Attending the Muscat workshop reaffirmed that cancer is a global issue and a global approach is needed to end this disease. I learned that while the action each of us takes is important, we need a strategic approach to combat cancer. We were able to hear the patients' point of view, and while participating in this wonderful workshop, I met and worked with such great advocates from around the world and it was quite interesting to hear their different takes on various topics.

Mrs. Yuthar Al-Rawahy, Founder and Chair, National Association for Cancer Awareness, Muscat, Oman

At the end of the workshop I realised there were many concerns we have not addressed as an association and I was able to get constructive feedback.

I would like to thank ICCCPO for organizing this workshop; the contacts and exchange of experiences with various participants from around the world were all pleasant, comprehensive and valuable. •

# Survivors

## NEWS FROM ST PETERSBURG

### Together for 10 years!

**When your cancer child is sick, it seems the whole world is against you. It is vitally important to have somebody on your side to rely on; to feel support, understanding, compassion and help. All these most significant and important things are provided by the non government regional organisation “Children and Parents Against Cancer” ([www.capac.ru](http://www.capac.ru)) in St Petersburg and its energetic young executive director Katerina Kiseleva.**

Children, former cancer patients, their parents, paediatric oncologists, medical nurses, volunteers, journalists, members of other organisations helping disabled people—all those who are kind enough in heart, brave enough in soul and wise enough in mind to really help cancer children, met together for a family gathering to celebrate the 10th anniversary of this unique organisation.

It was a meeting of a really big family with more than 100 members, who met on board the ship “Gardemarine”, sailing along the Neva river in the most beautiful city in the world—St Petersburg.

It was a normal family gathering: kissing and embracing, crying from happiness and joy, meeting old friends, who spent months and months in the same hospital. giving flowers and applauding doctors who could hardly recognise their former patients, now charming energetic teenagers. Sharing memories and photos among parents who supported each other during that most challenging and hard time when their children were sick, singing favorite songs and dancing together, eating fruits and candies, even drinking a sip of champagne provided by a silent kind president of CAPAC, Roman Yavorsky, who sponsored the whole gathering.

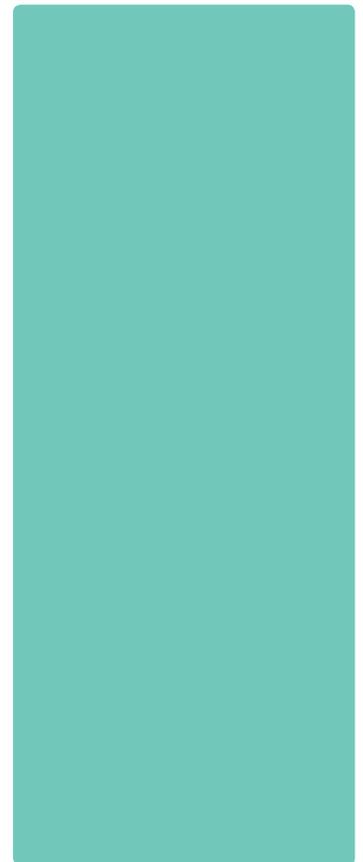
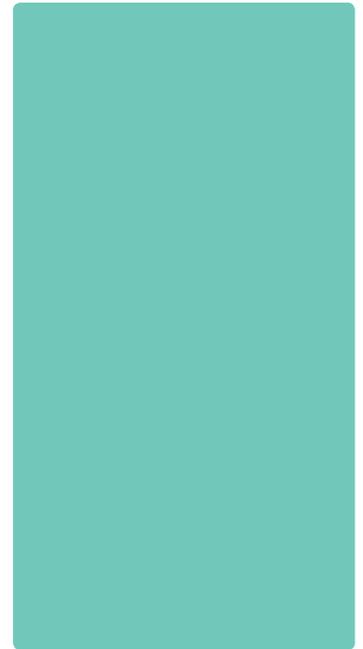
Friends were invited from Moscow (non-governmental organisations), and Helsinki (Finnish parents group “Sylva”).

Everyone was united in celebrating the victory of life over death, health over illness, joy over sorrow, kindness over cruelty.

CAPAC is unique, because it really helps: without big speeches, official promises, great applause, it has helped people EVERY DAY during the last ten years, by:

- collecting money for expensive anti-cancer drugs,
- buying cakes and toys for birthday celebrations,
- inviting artists and clowns for concerts in the hospital,
- organizing a bus trip for former cancer children on a sightseeing tour to Novgorod or Helsinki,
- providing summer recreation in the “Solnyshko” sanatorium,
- sending cancer children and teenagers to a Serious Fun session of therapeutic rehabilitation at the International Barretstown Gang Camp in Ireland,
- organizing a conference of different parents’ organisations in Russia and the former USSR republics to exchange their experience in helping cancer children and their families,
- publishing a monthly newsletter “Hello”,
- publishing a magazine “Together”,
- and doing many, many other things that help cancer children and their families during illness and after it.

At this meeting there were no official speeches and serious reports, except when a world-famous paediatric oncologist, Dr



Continues on page 20...

# Survivors

## NEWS FROM ST PETERSBURG

Continued from page 19...

Margarita Belogurova MD, read an address from a deputy of the St Petersburg City Parliament, Oleg Sergeev, greeting the CAPAC organisation.

Much more touching was to see the surprise of this doctor, when she looked at a tall, handsome boy and could not recognise her former patient. Only when she saw his mother did she guess that it was a boy she'd successfully cured several years ago.

It was hard to keep from crying when a boy in a black tie—Gosha Bondarev—and his mother embraced St Petersburg social journalist Galina Artemenko, who had helped to raise money for his expensive earphone last year. She could at last see the real result of her work.

It was a great moment of joy to see a teenager, Anton Rybchinskiy, who was the first to go to Barretstown 8 years ago. Since then he has entered and graduated from the Institute of International Economic Relations, and was now helping to drive guests to and from the meeting.

Renata Ravich, coordinator, Barretstown Gang Camp in Russia

Everybody laughed like mad, enjoying funny teenagers who danced like “little swans” in the ballet “Swan Lake” in dresses. Only their mothers and doctors knew what a rare form of cancer one of them had almost 11 years ago.

Common memories of sadness during illness and happiness after cure, satisfaction with the great work organized by CAPAC, wonderful memories of trips and gatherings, common hopes and serious plans for future, new ideas for development and enlargement of the CAPAC organisation. This all proves that CAPAC, even though it's only (just!) ten years old, is going to grow like a teenager and provide help and support to all those cancer children and their families in St Petersburg.

Happy birthday, dear children, parents, medical professionals, specialists, volunteers and managers of CAPAC! Many happy returns of this wonderful day! •



## News from The Board

### **There have been exciting developments with the World Child Cancer Foundation.**

We have made some good progress, with over 500,000 Euros in total funds donated and firm pledges through bank orders. We are progressing more personal contacts through the trustees and hope to increase funds further in the months ahead.

Terry Hunt, our Marketing Trustee, feels strongly that we need to have projects operating to attract new donors. Terry would like to use stories from the frontline of these projects, and to use the doctors and carers to demonstrate “solutions” and encourage further support. The trustees generally also feel that having projects operating would move the Foundation forward and show people who have already donated funds—including you as founder donors—that the money is being used to deliver help.

At the last Trustee meeting, it was agreed that two initial projects will be offered funding, one in Latin America linked to St Jude, and the other in Africa linked to SIOP. In both cases we will have ICCCPO input. Over the coming months we will be talking to potential project managers and seeking a plan from each. Once these are agreed within the criteria of WCCF, we will announce further details.

Criteria for selection includes having a good network locally; good twinning links with developed countries; clear outcomes planned for children and families; and a sustainable plan beyond the Foundation funding. Foundation funding will be offered for 5 years initially, to help ensure the projects have the best chance to work. The Trustees plan to commit over 300,000 Euros to these two initial projects, and look to recruit a fundraiser later in the year.

The commitment to date from ICCCPO Founders is 100,000 Euros, and we hope to increase this to 150,000 Euros thanks to support from other members.

We will keep you in touch with progress.

## Medical News (SIOP)

### Meeting between ICCCPO and SIOP Europe

ICCCPO and SIOP Europe enjoyed a successful joint meeting on 19 March 2008.

Together with the SIOP Europe President, Professor Kathy Pritchard-Jones, and two SIOP Europe staff, Samira and Jocelyne, 21 ICCCPO delegates from 15 countries enthusiastically exchanged opinions on various topics. These included:

- how to improve the communication between the patients (parents) groups and the paediatric oncology professionals
- how to strengthen the joint input in relation to childhood cancer related policy at both national and European levels
- how to build on the collaboration between ICCCPO and SIOP Europe over the term ahead.

This fruitful meeting not only enriched the communication between the umbrella associations (SIOP Europe and ICCCPO) but also concluded with a joint proposal to revise the document on the 'Recommendations for the organisation of a paediatric cancer unit.' •

Marianne Naafs-Wilstra

## Annual Meeting 2008

### See you in Berlin!

We hope to see you all in Berlin, Germany, between 2nd and 6th October 2008, for this year's ICCCPO meeting, along with the 40th SIOP conference.

The Local Organising Committee (including Gerlind Bode on behalf of the parents) is busy getting things organized so that this will be a wonderful experience and a fruitful conference for all. The "program-committee"—including Anders Wollmén, Anita Kienesberger and Prudence Walker-Cuttance—is working hard to create an interesting program for parents and survivors. We've included a rough program below, and you can find the "program at a glance" on the SIOP website. We will send updates to the specific parents/survivors program regularly by email through the ICCCPO secretariat.

If you haven't yet done so, please be sure to register soon and book a hotel room in Berlin. You can do this through MCI (the

official SIOP agency) or simply go to the website and find hotels in Berlin. There will be other large conferences in Berlin at the same time—so don't delay!

Though Berlin is a relatively large city, public transport is very convenient and you don't have to find a place close to the ESTREL (the conference location) as long as you find somewhere close to an S-Bahn or subway (U-Bahn) stop.

Specific questions about the location can be answered either by the MCI or possibly by Gerlind Bode, though she is not a "Berliner" ([gerlind-bode@t-online.de](mailto:gerlind-bode@t-online.de)) and questions about the program can be answered by Anders Wollmén ([anders.wollmen@bredband.net](mailto:anders.wollmen@bredband.net)).

Continues on page 23...

# Annual Meeting 2008

Continued from page 22...

## Full details

### Registration

Everyone MUST register online with SIOP this year at [www.siop2008.de](http://www.siop2008.de).

The costs for parents and survivors are:

- Regular Registration, up to 31st August: 400 Euros
- Late registration, after 31st August: 500 Euros

For the first time we now have categories for both parents and survivors, so please make sure you tick the right box.

You can register online at [www.siop2008.de](http://www.siop2008.de).

If you are receiving a scholarship from the Parents Helping Parents Fund, you will be able to register online at the early rate even if you miss the early registration deadline.

### Hotels

You can register online for a hotel when you register for the conference. We strongly advise you to make your reservation as soon as possible to ensure you get your first choice. The longer you wait, the more difficult it will be to find a hotel to suit your criteria.

Please note that room rates in Berlin sometimes don't include breakfast.

### Parents Helping Parents Fund

As usual we are looking to our friends in developed countries to help parents from less fortunate countries. Please ensure that you budget for a scholarship (or two) in the amount of 500 Euros, to help those who need extra help to attend.

Sponsorships for meals and social events are already being sought by other members,

groups and companies to make it even more affordable. If your group can sponsor one of the social events, please let us know—it would be most appreciated.

### Poster competition

We would like to receive abstracts for posters on any topic suitable for this visual medium. There will be a cash prize awarded to the author of the best poster.

### Program

We are working on the program and have included our preliminary program here. However, it may well change, since we are still at an early stage.

### Thursday 2nd October

We start our program after lunch with workshops. These workshops will not be at the main conference venue. We plan to have the "Meet & Greet" at the same location immediately after the workshops.

### Friday 3rd October

We will have our opening ceremony and opening sessions before lunch and continue with sessions after lunch. In the late afternoon the official SIOP Opening Ceremony with José Carreras will take place. Find out more at [www.siop2008.de](http://www.siop2008.de). We will launch the "Through my eyes" photo exhibition, presenting a selection of posters from the last three years' exhibitions.

### Saturday 4th October

In the early morning we start with a new event, "Meet the experts", for parents and survivors. We will be able to ask general questions to experts on selected subjects (the subjects are not chosen yet), followed by presentations by prominent people. In the afternoon we will have the Interactive Board

### VISAS

Letters for a visa can be requested at [siop2008@siop2008.de](mailto:siop2008@siop2008.de)

### IMPORTANT DEADLINES

#### July 31, 2008:

Deadline for Hotel Registration

#### August 31, 2008:

Regular Registration Deadline

### DATES AND VENUE

The conference will be held at The ESTREL Convention Centre, Berlin, Germany.

The conference and workshops begin at 13.00 on Thursday 2nd October 2008, directly followed by the Meet and Greet. The conference ends on Monday 6th October.

The workshops, Meet & Greet and ICCPO annual dinner may be held at another location. Look out for further information in our upcoming announcements.

Continues on page 24...

# Annual Meeting 2008

Continued from page 23...

Session and Annual General Assembly. And in the evening it is time for the ICCPO Annual Dinner.

## Sunday 5th October

On Sunday we are planning joint sessions and there will also be a Board meeting for the newly elected Board. In the afternoon we are trying to arrange a hospital visit at the Charité Virchow Klinikum.

## Monday 6th October

A day of joint sessions, ending with a general closing ceremony.

We'll keep you up-to-date on the program development and sincerely hope you will consider coming to Berlin, present a lecture or poster and fully participate in what is sure to be a very exciting program, both from a learning and sharing perspective. In the meantime, you can view the ICCPO preliminary program on-line at [www.icccpo.org](http://www.icccpo.org) and the full conference details at [www.siop2008.de](http://www.siop2008.de).

All the best to you and your organisations, as you help children with cancer to survive and thrive! •

**Anders Wollmén**, Chair, ICCPO Parent's Program Vice Chair, [anders.wollmen@bredband.net](mailto:anders.wollmen@bredband.net)

**Anita Kienesberger**, ICCPO Parent's Program, [dachverband@kinderkrebshilfe.at](mailto:dachverband@kinderkrebshilfe.at)

**Prudence Walker-Cuttance**, Chair, ICCPO Survivor's Program, [iccsnetwork@gmail.com](mailto:iccsnetwork@gmail.com)

**Gerlind Bode**, Local Organizing Committee, [gerlind-bode@t-online.de](mailto:gerlind-bode@t-online.de)