ICCCPO

International Confederation of Childhood Cancer Parent Organizations Vol. 13/No.1, 2006

ICCCPO Newsletter
Spring 2006
Volume 13, No. 1
Published two times per year

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Si preferien recibir este bolentin en la edicion en castellano, por favore porganse en contacto con la Secretaria de ICCCPO en Hollanda.

A few words from the editors ...

When the ICCCPO board met for its mid-year meeting in Heidelberg (Germany) it was decided that from now on the ICCCPO-Newsletter should be sent out only in a digital version only - thus saving us a lot of money in printing and shipping costs. We are trying this possibility here for the first time and would like to hear your reactions. You will be able to print out the pages on your own printer – and if you have access to a colour printer, the photos can be reproduced even in colour. Please keep in mind that the quality of the photos might be somewhat less than it would be for a "real" printing job. If you have difficulties at all to download a paper version from this format, please contact us and we will forward a print-out to you.

As you can see on the enclosed pictures of the board in Heidelberg, it was still very winter-like, though already March on the calendar. The German Leukemia Foundation hosted the board in its Campsite which is situated in the forest of the city of Heidelberg. Thus all of them could have a look at the camp and could be introduced to the two parent groups which were also there for a weekend seminar.

Much work could be done during those days – among others the preliminary program for the coming ICCCPO/SIOP – meeting in Geneva (September 16-21, 2006). Look for updates under www.ICCCPO.org.

This year's ICCD was again a great success. Many activities were organized around the world (s. pictures and reports on the following pages). Photos taken by the patients on the topic "My School" will again be part of a large exhibition at the ICCCPO/SIOP conference.

Please make sure you look at the ICCCPO-Website; under "Workshop presentations 2005" you will find valuable information and handouts (as word.doc) from the ICCCPO-workshops in Vancouver on the topics:

- Priority setting, benchmarking and evaluation
- Volunteer management
- Fundraising for groups in developing countries
- Marketing and branding your organisation.

Gerlind Bode, Marianne Naafs

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www.icccpo.org

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(pictures sent by CLASS)

ICCCPO 2006
Asia Parents' Meeting in Shanghai

ICCCPO Asia 2006 Parents Meeting was held in Shanghai, China between 6th & 7th April 2006 in conjunction with SIOP Asia 2006 Conference. There were 76 participants from 12 regions / countries attended the two days ICCCPO Asia regional meeting; with 16 from greater Shanghai area, 14 from Guangdong province (South of China), 19 from Hong Kong, and 27 from other countries.

Objectives of the regional meeting were to:

1. reinforce the mission of ICCCPO "to share information and experience in order to improve access to the best possible care for children with cancer everywhere in the world" and particularly in Asia.

2. to strengthen connections between ICCCPO Asia members, and
3. to see what ICCCPO can do for the vast country of China with no formal local or national parent groups yet.

To achieve these goals, the 2 day program included each of the participating members/groups sharing their experiences and activities, a sharing session with medical professionals, interactive sessions between all participants and also a solo interactive session by Chinese parents.

The meeting resulted in having 2 parent groups in China formed after the interactive session towards the end of meeting; with one in the Shanghai region and one in the Guangdong region. ICCCPO Hong Kong members will keep on offering support to the newly formed parent groups in China and expecting the relative SIOP members in China to offer support and co-operation too.

Also through the collaboration between SIOP Asia and ICCCPO members prior to and during the ICCCPO Asia 2006 Parents Meeting, ICCPO forged a stronger link and better working relationship with the regional SIOP.

Furthermore, it was nice to hear during and after the meeting from members and parents who attended the meeting that they wanted further Asia regional meetings. This showed the enthusiasm of the participants and their willingness to meet together regionally.

The successful Asia regional meeting is the collective effort of the organising committee which consists of parents and volunteers from Hong Kong working together with an/the organising team from Shanghai Children Medical Center. It is a challenge to balance the interest and enthusiasm of all participants with language barrier, as about half of the participants are not English proficient (only Chinese). The organising committee had to prepare a Chinese translation of all presentations prior to the meeting and hand it over on the spot to participants from China so they would be better able to understand the translations of the presentations in English. Also two live interpreters, volunteer students of language school in Shanghai, were there to summarize each English presentation, translating into Chinese and vice versa. This was a good lesson that we should consider dual language meetings where there is a high level of non-English speaking participants.

We would like to take this opportunity to thank the volunteers from Hong Kong, the support of Shanghai organizing team lead by Professor Wang - Chair of SIOP Asia 2006 Conference, the volunteers from Shanghai, and also the generosity of Shanghai Children Medical Center for the use the hospital conference center at no cost for the meeting on 7th April.

Benson Pau
Chair of Organising Committee
ICCCPO Asia 2006 Parents Meeting

2nd Regional Meeting of Childhood Cancer Parent Organizations in Countries of Former Yugoslavia

The second Regional meeting of Childhood Cancer Parent Organizations was held in Split (Republic of Croatia) on 12 of May 2006 with the participation of 27 representatives from 5 countries from ex-Jugoslavian areas: Macedonia, Bosnia & Herzegovina, Serbia & Montenegro, 8 local Croatian groups and, for the first time, 2 organizations from Slovenia. The meeting was organized by the parent organization from Split "SANUS" with generous support from ICCCPO. Mrs. Bozena Anic, president of SANUS, welcomed us warmly.

The meeting went on in a working atmosphere, in an exceptionally good mood, and the participants shared many emotions, tears but laughter as well. Everybody got the chance to present the activities of their respective associations; to outline the latest achievements in the field and to present the difficulties they are facing with their activities. Physicians held exceptional lectures, intended for the parent audience. A great many representatives of governmental institutions pointed to notable co-operations they managed to establish with the parents from Split. The Minister of Health of the Republic of Croatia attended the meeting as well. He was also deeply moved by our joint initiative and cooperation.

Anita Kiensberger (new ICCCPO board member) gave a presentation about the ICCD and demonstrated all possible models and examples for parent organizations. On behalf of the ICCCPO, I introduced its history, mission, goals, benefits of being a member and programs such as regional cooperation, twinning programs, gathering local groups and establishing umbrella/national organization etc.

Despite our very poor and difficult economical situation and the fact that money is the precondition to enable maximal treatment possibilities, we are of the opinion that there is something - even more important – which is information and education, both of patients and their parents, as well as of the whole public.

- Despite the fact that course for clinical pyscholgy exist at the universities, psycho-oncology is an unknown branch of psychology in all countries of former Yugoslavia. It means that both children and parents are left to themselves and Parents' Associations are their only "window to the world".
- Medical staff also face great problems since they experience "burn out" as a result of the lack of expert psychological help and support.
- Upon a child's re-established education, there is no cooperation with the schools. Children and their parents are left alone to manage and overcome hard situations; educators also face many problems since they do not know how to deal with a cancer sick child that attends school lessons.
- Just a few children know the truth about their disease and survivors are isolated and are ashamed to have an open talk about their diseases.
- Parents are ashamed and afraid of the disease.
- Many physicians (not all) place themselves in the role of Gods, thus not inclining towards the idea to have parents as partners in the treatment.
- There is a prevailing attitude that places the parent's organization in the role of a service intended to serve the needs of the hospital and its medical stuff.

This is just a small part of the problems we face every day which are definitely not connected to the matter of money. Both parents and physicians, from all countries, are very interested and need twinning with other groups/hospital.

The time passed so quickly and we all wished that we could have more time for workshops and specific discussions, not only presentations. Therefore, our next meeting will be better organized in that respect. Though Slovenia is the most prosperous country in this area, there is still no parent organization and this meeting was a good opportunity for them to realize the significance of a parents' group. They have been so impressed with our enthusiasm and realized that it is not enough to have humanitarian support institutions (or some other kind of support groups), good physicians and nice hospitals. They are well on their way to establish their first parent organization in Slovenia.

Despite of all our differences and the bad reputation of our recent history, we are still just people, parents of cancer children who have faced a lot of pain and our experiences are almost the same. The most important fact is that we still have a similar language, mentality, legislation and therefore we are able to accept from each other different models of projects and activities. The set of circumstances is something very important for organizing further regional meetings amongst former Yugoslav countries.

The 3rd Regional Meeting will be in Sarajevo (Bosnia & Herzegovina) in May 2007 and we would like to invite the Chair of ICCCPO, Mr. Simon Lala, and other board members to join us.

Irina Ban, Belgrade

Giulio J. D'Angio

SAFE TOBACCO ?[1]

Important message: don't trust tobacco companies. They are marketing "Safe" tobacco products, advertised as tobacco harm reduction (THR) items. They are unregulated and not subject to testing by governmental agencies such as the USA Food and Drug Administration. The goal of the tobacco companies is to attract young persons and turn them into new users. They also target developing countries where there is a huge market waiting to be exploited.

The conduct of the industry has led Dr. Fiore to list what he has called, The Seven Pillars of Fraud.[2]

Over the years, tobacco companies have

- Denied any harm from direct and indirect smoke inhalation
- Claimed that tobacco-sponsored "research" was independent
- Suppressed unfavorable results
- Denied that nicotine is addictive
- Manipulated nicotine levels in cigarettes to create addiction
- Marketed products with misleading labels; e.g., "light" cigarettes
- Focused on youth

The focus on youth is especially ominous for childhood cancer survivors, many of whom are just past childhood. They are vulnerable to added damage to organs that may already be impaired from prior Chemo- (CT) &/or Radiation Therapy (RT); especially the lungs. They also are at increased risk of developing a second malignant or paramalignant condition, such as Langerhans cell histiocytosis (LCH).[3] LCH and childhood cancer follow each other like shadows.[3]

Moreover, LCH of the lungs is strongly linked to tobacco smoking.[4]

A whole issue of The European Journal of Cancer recently was devoted recently to Cancer Chemoprevention.[5] All those concerned with the well-being of the patient cured of childhood cancer – family, friends and physicians – can help prevent cancer and disability much more simply and directly. They can do this by helping to guide the health habits of young survivors. Perhaps the least intrusive site and most objective four walls are those of the long-term follow-up clinic. There, many questions relevant to health status are asked. When it comes to smoking, staff members can and should ask probing questions after making the 3 key statements:

- DON'T SMOKE
- STOP SMOKING IF YOU'VE STARTED
- STAY OUT OF SMOKE-FILLED ROOMS

Close questioning must go deeper. Has there been any thought of trying a flavored cigarette? Some have enticing names like, "Twista Lime" and "Warm Winter Toffee". Has the person been tempted to try a non-inhalation, nicotine-containing item such as tobacco "candies" (flavored compressed tobacco leaves), or nicotine-containing waters and juices?[6]

There is danger in starting in going down that road. These cigarette substitutes may prevent smokers who wish to kick the habit from doing so by keeping them satisfied in a smole-free work-place or school until they go home where they can smoke. The hazards to themselves and to those near them are thus perpetuated. In both men and women, the link between smoking cigarettes to lung cancer, heart disease and debilitating pulmonary diseases such as emphysema are widely known.

Cigarette smoking kills > 400,000 Americans/year, most from lung cancer, with heart and lung disease next. More die from smoking than automobile accidents, gun shot wounds, AIDS, fire, and drug and alcohol abuse combined.[1] Most of the deaths are secondary to lung cancer, with lung-related disability; e.g., emphysema, and heart disease next.

More than 1/3 of all deaths for the middle age group, and more than 1/6 deaths overall in America are attributable to smoking. For every such death, there are 20 patients chronically ill, mostly from pulmonary and cardiac problems.

Not so well appreciated is the fact that the risk of breast cancer in pre-menopausal women is higher in smokers and in those subjected to second-hand smoke.[7] Recently, evidence of an increased risk of cervical cancer in smokers has been published.[8]

There are more than 6000 compounds in cigarette smoke. There has been no health advantage from filters (more tobacco was put in cigarettes to make up for lost "taste"), or from low tar, nitrosamine and catechol blends. Moreover, interventions to restrict cigarette sales have had no effect on 'teenage smoking.[9]

Thus, while there are relatively safe smoking substitutes like those pioneered by the Scandinavian nations, notably the Swedish product, "snus," it is a better strategy to say there is no safe tobacco.

Summary

All those close to the patient can help prevent avoidable illnesses by discouraging the use of tobacco products. The staffs of late follow-up clinics can add prophylaxis, which is the backbone of pediatrics, to surveillance as an important part of their mission. It would be tragic indeed should a child survive the rigors of cancer and its treatments only to succumb as a young adult to a preventable lethal disease caused by smoking

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Warning Signs for Cancer in Children

prepared by the South African Children's Cancer Study Group and sponsored by CHOC Childhood Cancer Foundation South Africa

In less developed countries, very few children receive effective treatment for Childhood Cancer. One major reason for this is that, if the disease is diagnosed at all, it is frequently at such a late stage as to make the prognosis for successful treatment very poor.

In South Africa, there are several excellent treatment centres, which use internationally accepted protocols, and achieve results comparable to hospitals in North America and Europe for similar stages of diagnosis of the illness.

However, in some of the communities, there may be over 80% of children diagnosed with tumours in the late stages, compared with some 15% in developed countries.

In an attempt to improve this situation, the South African Children's Cancer Study Group, which includes all of the specialist paediatric oncologists in the country, has prepared a set of Warning Signs.

These have been made into posters, in English and Zulu, which are being distributed to the Primary Health Care Clinics across the country, starting initially in the northernmost provinces.

A toll-free help line has been installed at the Chris Hani Baragwanath Hospital, where the sisters or doctors at the primary health clinics can phone for advice as to whether the child needs to be referred for further investigation, and which unit they should be sent to.

Dr Stelios Poyiadjis, one of the specialist paediatric oncologists at the Chris Hani Baragwanath Hospital (in Soweto, Johannesburg), has been very instrumental in the development of these Warning Signs. He has visited the staff in the primary health care clinics to educate them about the Warning Signs.

The English version of the poster is shown below; a Zulu version is also available.

The posters that are distributed to the primary health care clinics are of A2 size, and have high quality printing.

The printing of the posters, and the funding of the toll free line, has been sponsored by the national parent organisation in South Africa, the CHOC Childhood Cancer Foundation South Africa.

The St Siluan Warning Signs have been accepted by SIOP for use in all developing countries.

Sadie Cutland
CHOC – Childhood Cancer Foundation South Africa

www.choc.org.za/warning_signs.html

Expressing the unexpressed: a way to survive

Staying close when having a child with cancer is not easy. Your skills are challenged to the utmost. From the moment of diagnosis 'normal' life ceases and may never return to what it was before. How do relationships survive?

In this presentation I want to give you some tools to survive. And if it's not for yourself, please care for the parents who stand at the beginning, who have to support their child on the long way of cancer treatment, who face the death of their child or who care for a child that survived.

They are all struggling in their own ways with fear, anger, sorrow and pain. Maybe you – as parents, doctors and nurses - can give them some professional, personal or parental advice.

don't come closer
I want space
to feel
to think
to get things clear

Give me space
but please stay close

Marina San Giorgi

As a psychologist I work with children and adults with cancer. Sometimes the child has cancer, sometimes the sib, sometimes the parent. I have a suitcase full of stories. And honestly I don't know where to start. Should I tell you about eight-year old Susan who lost her mother and is afraid of getting cancer herself? Should I tell you about 13-year old Chris who lost his father and doesn't want to sleep in his own bed, but at the same time feels stupid? Should I tell you about 37-year old Caroline who lost both breasts? Should I tell you about Tim and Anna who lost their trust in the future? Or should I tell you about Wilke who said: the only positive thing about my cancer is that it brought my parents back together?

The disadvantage of psychologists is that they start with stories about sorrow and pain. Stories about people in trouble. Because that's why people go to psychologists. 'When I look at her, she is so far away. We are in separate worlds. Each on our own island. How can we come closer?' But the good thing is they can end with stories of 'coming more together' and 'feeling more intimate' Because closeness and intimacy are look-alikes I want to start with some different forms of intimacy.

Intellectual intimacy. Intellectual intimacy: the exchange of important ideas and topics can create intimacy. Hopefully there is intimacy between us, because you are interested listeners. This can be the same between parents. When there is intellectual intimacy, the distance between parents is small. Both parents communicate on the same level.

"My partner and I both love to read and exchange ideas. We always have something to talk about"

Physical intimacy. Look around and you will see what I mean. Rocking a baby, the embrace of mother and child, sitting close to a friend, a kiss, a hug, touching each other, holding hands, all are forms of physical intimacy.

"Four-year old Simon diagnosed with a brain tumour is very ill. He only wants to sit on his mother's lap"

When a child has cancer it's not only the child who needs physical comfort. Also Parents too long for physical intimacy. They can feel very lonely.

"I was in the hospital with my son, 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 son with cancer, the other children, my work, it was all too much"

The child survived, but this couple had to start again.

Sometimes it's the other way around. In the next example the mother is in shock

"I couldn't do anything. I just sat on the couch. I didn't want anyone to come near me. I just didn't want it"

Physical intimacy can function as a trigger and that's not easy for parents in despair. Afraid of breaking down and never stop crying again, they don't want an arm around them. On the other hand they are longing for a sign of physical comfort, because they feel so lonely. Again a little poem:

Don't touch me
because I'm going to cry
Please touch me
because my tears are high

Parents who are able to share their pain - how desolate they may feel - can give mutual comfort.

And what to do with the sexual relationship? Making love as parents of a child with cancer is most of the time very emotional. And sometimes the child with cancer sleeps in the parental bed or bedroom, which makes love-making almost impossible.

Yesterday it was the first time that we made love. Afterwards I cried a lot. It was so contradictory. Nice that everything was normal, but at the same time an overwhelming feeling of guilt. Is it possible to enjoy love making while your child has cancer?

'Let's go back to another type of intimacy: emotional intimacy i.e. exchanging important feelings. For most adults talking is one of the most important ways of exchanging feelings and ideas. But talking - and especially talking about your feelings - is not always easy. Fathers in particular found it difficult to talk about their feelings.

A father: *"I've always found it hard to talk about it. My wife is different, more open. She can talk to everyone. I don't"*

Exchanging important feelings doesn't always need to happen in face-to-face encounters. Sometimes it's even nicer when the person you love the most isn't there at the moment. It can be safer.

"We used to send each other letters when we are younger, now talking is so painful we started writing letters again"

"I love you, come home soon. XXX" (SMS message)

If we define intimacy as being close to another person, then shared activities can provide another way to achieve this state. Not only doing things together with the whole family, but especially partners spending time together. Quality-time.

The 10-year old twin daughter of Iris and Mark is treated for a relapsed Hodgkin's disease. Medically everything seems fine, but the child is very depressed. She is very tired, can't go to school by herself and is jealous of her twin sister who seems to have enough friends. She doesn't want to see a psychologist (she really hates professionals) so her mother asked for help for herself. After a few months of advice for the mother, the father stepped in. He was depressed too. He claimed that there was no time left for him and his wife together. They shared the pain, but not the nice things. Everything revolved around the twins. Half a year later they enjoyed a dinner for two for the first time

Be aware: not even the closest relationships always operate at the highest level of intimacy. At times parents may share all their thoughts and feelings with their partner, at other times they may withdraw. Or they may freely share their feelings about one topic but not about another.

Of course there are cultural differences in intimacy, at least in the expressing of intimacy. In some cultures husband and wife are not allowed to express their feelings in public, they are not allowed to walk hand in hand, to look or talk to each other. We all have our own values and standards. But being grown-up in a society with strictly separated roles will surely affect the closeness you need so much as parents of a child with cancer.

So how to keep your relationship clear and alive if your child has cancer?

In each relationship one has to work, in times of a crisis one has to work even harder.

If parents want to come together or if they want to prevent troubles growing beyond their control they have to talk to each other. Talk about their feelings, express their sorrows, their anxiety.

Some advice for parents in despair:
Choose the right time and place, don't ask for attention when your spouse is too tired to receive anything, not when he or she has 5 minutes to relax and not when he or she just starts to go out (that's called the doorknob-method). Don't choose to express your feelings in the supermarket, or on the stairways of the hospital but choose a quiet place where you can be yourself and a moment that is the best for both of you

(When parents were asked about the right time and place to talk about their feelings many of them answered: in the evening when the children are in bed and we are enjoying a glass of wine. Others say: while walking together along the beach, while having dinner together, while washing the dishes together or while sitting in the car going to the hospital. The most important thing is that parents make and take time for them together!) Be clear and honest, don't think half words are enough because you understand each other fully. You know the sentence: but I thought, that you thought, that I thought? Stimulate each other – and other parents - to be clear and honest. What do parents expect from each other? In what way can they support each other?

Don't be afraid to show your emotions, sometimes parents try to protect each other by not showing their emotions. That sounds nice but is almost impossible to maintain. They also miss the chance to share.

Don't deny the other person's feelings, don't say 'You don't have to be afraid', or: 'It's ridiculous to feel guilty'.

Try to retain hope

But what if talking is not your style?

We have to accept that some things never change. If talking was not the style before the child was diagnosed then it will be not now. Fathers who find it difficult to talk to their children are not by definition bad fathers. Playing soccer with your child is also communication. Mothers who have difficulties in saying 'I love you', can show their love in other ways. But: it can be a problem if one hás to talk.

In my practice I talk with many men and women. They all start with 'I don't know what to say' (or my wife sent me) and they all talk till the end.

For parents it's important to know that there are lots of other ways to 'talk'. Writing a letter is one of the best examples. Draw a kiss on a paper, send an SMS, write a mail, draw a picture, buy some flowers, sing a song, or: go out together to share some activity.

One more thing: Not knowing how to communicate or 'how to come off your own island' is normal when your head is full of sorrow. Stimulate parents to think about what they did before their child was diagnosed. How did they interact before? How did they solve their problems? What was good and what of no use? It's in their system! They only have to pull it out.

Professional support

If troubles are too much, if there is no way out, don't hesitate to ask for support. Psychologists are not so bad. (You look very normal! commented a 10-year old client, last week). And of course there are other psychosocial workers. It's good to put your suitcase full of sorrows on the table of a professional.

It's not a sign of weakness to go to a professional, as most people think. On the contrary, it's a sign of power. Asking for support is taking good care of yourself. And it is never too late.

Ten years after the death of his daughter William came to talk about his pain. His wife didn't want to come, but after a while she started to come also - at William's request. She refused to talk because – she said – 'talking doesn't bring my daughter back'. I agreed with that, but the problem was she néver talked about her daughter. The two other children didn't dare to talk about their dead sister either, because if they did their mum burst out into tears. They had a lot of questions. Individually and together they talked a lot with me and each other about how to handle the pain, I even went to their home. William considered a divorce. He couldn't handle the situation any longer, but he decided to wait. Little by little the mother started to talk in her own way and in her own time. Together they made plans for the renewed memorial of their daughter and sister. It was painstaking for all of them. I will never forget William's tears

As he said: why must it be so long before we talked about this? Why not eight years before? I told him that everybody follows his or her own path. There is no time, there is no place, there is only one way to survive: to express the unexpressed at your own time and at your own place.

drs. Nel Kleverlaan, psychologist,
Dutch Association of Parents, Children and Cancer, the Netherlands

Regional Group Reports

„Give love, because of our children - Give love, because love gives life...“

Successful year of the Association from Bosnia and Herzegovina

"Those who save one human life save the World". Yes, the Association "The Heart for the kids with cancer in FBiH" from Sarajevo, Bosnia and Herzegovina has been trying, since the establishment was founded back in 2003, to find a path how to help in healing, survival and re- socialisation of our little brave fighters - children with cancer in Bosnia and Herzegovina. The year 2005 was the one most successful year of our work.

The most important information is that, finally, we have our own business premises, settled near by Sarajevo clinic (just 300 meters from it). Within the area of 50 square meters we are now able (with the help of our donors and friends) to organize different kind of activities.

We have improved cooperation and coordination with the Hematooncology department of the Pediatric clinic in Sarajevo and their staff- doctors and nurses through direct contacts with the Head of Department, Dr.sci.med. Edo Hasanbegovi, As the outcome of that cooperation we have published back in November 2005, the first brochure titled "Handbook for the parents of kids with leukemia"- author mentioned doctor, in 500 copies (promoted during our Annual Assembly held in Sarajevo on 19.11.2005) and we are in the process of preapring the next one - "Handbook for the parents of cancer sick children" by the same author. The cooperation with the Pediatric clinic was shown as well during the preparation of the trip of cancer sick children to the Barretstown serious Fun camp in Ireland when, back in September 2005, doctors helped us choose the kids who will travel to Ireland back in September 2005.

During 2005 we had a very good cooperation with the EUFOR from Bosnia and Herzegovina as regards organizing the free of charge transportation of the cancer sick children from BiH to Italy for further treatment. Other sectors of cooperation were : Institute for Public health of FBiH, Institute for public health of Middle Bosnia canton and Institute for public Health in Herzegovina-Neretva Canton during "children week" in October 2005 when we organized humanitarian concerts with music schools within 8 cities of Bosnia and Herzegovina. The outcome of that action was not only the collection of funds for our activities but an increased awareness in the public opinion as regards cancer in Bosnia and Herzegovina. As it could be seen on our WWW site: http://srcezadjecufbih.tripod.com and/or http://srtcezadjecu.ba those concerts were very well accepted by the citizens of Bosnia and Herzegovina who helped us collect a total amount of 5,000 Euros.

In the same time we organized workshops for our survivors during the period of the Festival of volunteerism when our small survivors were making handicraft products (purses, handbags) which will be on sale during the period of marking of the International Cancer Sick Children day on February 15th of 2006. During afore mentioned week - on 07.12.2005 our group of survivors

has made a small theatrical piece which was shown to the cancer sick children in Hematooncology Department of pediatric clinic in Sarajevo.

Our delegation visited the oncology department in Tuzla hospital back in 2005 and handed over some gifts and some medicine to the said department. On New Year's Eve we visited the Hematooncology Department in pediatric clinic in Sarajevo and gave as a gift 50 New Year Eve packages (thanks to our donors) to the cancer sick children. As a continuum of our actions, in December 2005 we organised two parallel actions in Bosnia and Herzegovina: one in Sarajevo at the beginning of December when we sold donuts to the visitors of Big moll (big supermarket) and by thus earning some money for our activities. The second one was in Travnik when we got a certain amount of money by selling art work by an artist from Travnik during the auction on 06.12.2005.

The Association "The Heart for the kids with cancer in FBiH" continues to have an excellent cooperation with ICCCPO and our twinning organization Een Haerz fiir kribskrank kanner from Luxembourg and Mrs Marie Marthe Bruck Clees including contacts with other members of ICCCPO all around the World.

During 2005 we had a very good cooperation with the Associations from the Croatia (SANUS) and Serbia and Montenegro (NURDOR) and during the joint meeting back in May 2005 in Belgrade we agreed to continue preparing the organization of RAURDOR (Regional association of all simillar organisations from the area) and the next meeting will be in Split (Croatia) in May 2006.

Some of our plans for 2006 are: publishing the above mentioned second brochure; to be involved in the organization of ICCCD day in BiH on 15.02.2006; to participate within the manifestation "children week of the kids with leukemia" which organize Association Losev from Turkey, to participate at the Annual Congress of ICCCPO in Geneva (Switzerland) in September 2006; to organize (within all Cantons of Federation of BiH) manifestations during the "children week" in October 2006, to organize some of the seminars and workshops for the kids and parents and to establish the section of BH survivors within our Association.

Sabahudin- Sabi Had iali
President of the Association
THE HEART FOR THE KIDS WITH CANCER IN FBIH
Sarajevo
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The Holiday of Life Fund in Yakutsk

Regional Group Reports

In our area, childhood cancer has increased by 20 % in the last decade. The mortality rate of childhood cancer holds second place, while trauma and accidents come first. In the Yakutian republic of Russia, 206 children suffered from a malignant disease in 2004.

Oncologists have clocked up considerable achievements in treating this illness, which was believed to be incurable years ago. Now 80% of the children are likely to survive – if they receive the correct treatment in time. Over 50% of all patients can go back to normal life - if the help was on time and well-qualified.

In memory of their son Alesha, his parents founded the "Holiday of Life" - Charity Fund. It began working in March of 2003 and is the first and only non-government social project of this kind in our republic.

The "Holiday of Life"- Charity Fund is a noncommercial organization. The fund means that we look for voluntary donations, allocation of money from organizations and persons who arrange and organize events. Volunteers do this work exclusively free of charge.

"The Holiday of Life"- charity fund was founded with the purpose to help families like 'Parents to Parents"

- Gathering of information about the disease, the treatment and its cure in supporting the families
- Solving quality of life issues such as making conditions for treatment comfortable
- Contacting social organizations which are engaged in childhood oncology issues
- Setting up a family database of those who are affected by the disease
- Organizing events such as collections for the treatment of the patients
- Supporting the interaction for families with sick children and the medical institutions;
- Information, moral and psychological support
- Organizing trips for children free of charge
- Presenting pediatric oncology issues in the mass media.
- Making conditions for the treatment more comfortable
- We are trying to make it easier for everybody and have painted the medical institutions in bright colors.

Maintenance of the ward

The children's ward 5 of the Yakutian Republic Oncological Clinic was renovated in January 2004. The ward is now equipped with a refrigerator, a TV-set and a recorder. Besides curtains and bedspreads, tissue screens have been ordered. Father Mikhail (the priest of Nicola church) consecrated the ward.

Hot food for the patients

One of the most vital issues is the organization of hot food for the children and for their parents. Because of the medical institution's requirements and restrictions this issue is relatively complicated. But, parents are allowed to cook for themselves and their children. We installed microwave ovens and an electric oven in the oncohematology department.

Organization of free transport for the patients from their homes to the clinic and back

For the immune suppressed children it is not safe to use public transport. Thus, the fund organizes free transport for kids with oncological illnesses from their homes to the clinic. A great number of the families do not have their own vehicles, nor do they have enough money to pay for a taxi. Thus, we also transport them when the child has to come back for follow-up a year after treatment

Information, moral and psychological support

When a child's ailment becomes obvious, the family faces a crisis situation. A great deal of the families have difficulty coping with the situation - what they never thought would happen has become harsh reality. In hospital they get only medical help. Other kind of support do not exist. Under these circumstances with an extreme lack of time and enormous financial loads, the issue must be solved with the help of different departments. In this situation help from families who have gone through the same ordeals with a sick child can be the most effective way. Constant interaction with the medical care system and social services is vital.

- Integration of parents: The fund regularly holds informal parents' meetings with the aim to exchange experiences and to search for solutions to these problems. The major achievement is the feeling of not being alone with the illness and having an opportunity to talk to people who understand this problem outside of hospital;

- Law consultations: helping parents with all kinds of social rights and benefits, such as financial support for disabled children;
- Psychologists for parents - the Yakutsk State University psychological department volunteers;
- support for teaching at home and in hospital for school aged children.

Contacts with other social organizations

We prepared a "Family social adjustment" seminar in June 2003 in Moscow, where we contacted other parents' organizations. Children were invited to rehabilitation free of charge, which helps to improve their health and social life. We contacted ICCCPO as we felt that the international confederation is essential for us.

Arrangements

Festive matinees became a tradition in the children's support day at New Year. Invitation letters are sent to all patients. The activities include a circus and theatre performance, meetings with famous people, games, summarizing the genius power, handing presents to children.

Paper cranes aims are:

- Companionship; little patients can't visit arrangements in apartments and under the blue sky because their impaired immune system. The sole opportunity is mass media like TV, radio and publications. The advantages of such arrangements are meeting face to face, companionship, games, having an opportunity to get distracted and forgetting illness.
- A store of positive emotions and good mood; Psychologists note that children need positive feelings as their 1st step towards recovery.
- A long–term treatment isolates children from society. They become outsiders. Competitions and games (held on a holiday), indulging the winners make them feel confident, self-important and raise self-esteem.
- Positive feelings for parents: parents meeting other parents with children in a similar situation can help each other. To see those who accomplished the treatment and recovered gives hope which is absolutely essential for the long way to recovery.

Arrangements

Children escorted by parents (26 persons) visited a Christmas performance at the national circus RS(Y) in January of 2006. This was the start of a good tradition with enormous support for the sick child.

Organizing a database about oncological diseases in childhood.

The fund asks parents who have an oncological sick child to fill in a form. These facts are useful in generating a general picture of the morbidity in the region and finding needs and problems of the families with sick children. Different forms of state, medical, legal and social support must be proved as necessary.

Plans

One of the most important aims of the fund is to create a specific rehabilitation centre – a school for the psycho-social rehabilitation of families with children suffering from oncological illnesses. The lack of rehabilitation programs for these children leads to problems. A specific centre could find solutions for these problems. All medical, psychological and social problems of disabled children refer to the "life quality" notion .The specific centre for psycho-social rehabilitation of cancer patients and their relatives could help them to return into society socially active and integrated.

This idea was presented as a project under the title "Psychosocial rehabilitation of families with children who suffered from oncological illnesses" at the All-Russian competition "My social program." It was considered the best program from all represented projects.

We will have to find out how we can provide employment and carrier guidance to parents and their children.

Alena & Michael Atlasov, Yakutsk

These photos were taken during Cancer Camps in Indonesia

Kids in front of their room

Walk on the Rope game

Patients at Water Painting

Patients and survivors after their performance of a short drama: The Good and Bad Cells

Walk on the Rope game

Announcements

July 8 - 12, 2006

UICC World Cancer Congress 2006
Washington DC, USA
For more information contact: secretari-at2006@cancer.org
www.worldcancercongress.org

September 16 – 21, 2006*

ICCCPO Parents Meeting and Annual General Assembly
Geneva, Switzerland
The ICCCPO Annual Meeting will be held in conjunction with SIOP (International Society of pediatric Oncology) in Geneva.
Further details will be published on the website: www.icccpo.org as they become available
The coordinator for the parent / survivor program is Christine Wandzura. Contact her at: wandzura@kidscancercare.ab.ca
Local coordinator is Fränzi Würsch.
Contact: franzi.wursch@kinderkrebshilfe.ch
Please look also for information on the «Info-Market» on the ICCCPO-Website.
For SIOP-information contact: www.siop.nl

October 29 – 31, 2006

International Congress on Childhood Cancer (ICCC)
Tehran (Iran)
For more details contact:
Alireza Mosavi-Jarrahi
Cancer Institute Research Center
MAHAK Childhood Cancer Hospital
Oshon Blvd, Darabad, Tehran, I.R. of Iran
Email: Alireza.Mosvijarrahi@gmail.com
www.mahak-charity.org

April 5 –7 , 2007

Regional Meeting in Bali
The meeting will involve parents, patients, doctors, nurses and psychosocial staff.
It focuses on issues relevant to the Asian region.
For more details contact Ira Soelistyo, Email: yoai2008@indosat.net.id

October 30 – November 3, 2007

SIOP and ICCCPO meeting in Mumbai, India
More details: www.siop2007.in

SIOP Asia-2008

will be held in Muscaat (Oman)

World Oncology Camp 2007

Sponsored by the American Cancer Society (Great Lakes Division) and the YMCA of Greater Toledo, international camp activities are offered to patients (ages 12-16).
Where: Jackson, Michigan (USA)
When: June 2007.
There are also plans for an international young adult's camp (ages 16 –20).
If you are interested, contact:
Vicki Rakowski (Exec. Vice President) at:
Vicki.Rakowski@cancer.org

*Info-Market at ICCCPO Parents Meeting in Geneva

Over the years the ICCCPO-community grew from a small family affair to a big family happening. And it is getting harder to keep up on what is going on in each country or region.

In Switzerland we still have farmer markets. Almost every city keeps up with this lovely tradition. Usually once a week the farmers are bringing in their fresh produce and it seems as if everyone meets at the market. There is always time for a chat or a discussion.

We thought it would be nice to have an Info-Market in Geneva where we can share information and keep up with the services of each other. Our goal is to open up the communication and to make it easier to share project and ideas that are working as well as finding new ideas. Several of you have submitted abstracts that provided an overview of your organization or a program – but we have decided to host this market instead, so please tell us about your programs and services here, instead.

In the Geneva Convention Centre we have space for our Info-Market in the main area. This means that also nurses and doctors have chance to see the important work we are doing in each of our member organizations.

For the Info-Market we are asking you to include the following information to put it on a poster (1 x 1 meter):

- Name of organization
- Address
- National or regional organization
- How many years of operation
- Numbers of diagnoses per year
- Area served
- Programs in general; please describe your programs with a few words
- A sample of your brochures
- Highlight one program you believe is unique, special or working particularly well

You may also like to bring with you about 50 brochures.

Please let me know, by June 30, 2006 if you would like to present your organization at the Info-Market so that we can plan the number of spaces needed.

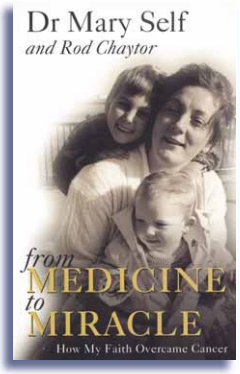
Looking forward to hearing from everyone!
Franzi Wursch
ICCCPO/SIOP Local Organizing Committee
Info-Market Coordinator
franzi.wursch@kinderkrebshilfe.ch

Books

Dr. Mary Self and Rod Chaytor

From Medicine to Miracle – How My Faith Overcame Cancer

London: Harper Collins Publishers, 2002.



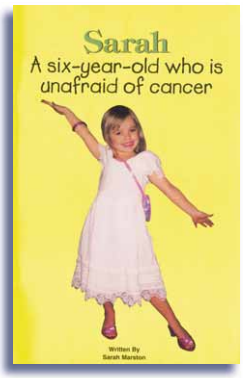
As a teenager Mary is diagnosed with osteosarcoma in one leg. She receives chemotherapy and the leg has to be amputated. Being a "fighter" Mary does not give up her dream of becoming a physician. She studies hard for the entry exams for medical school and gets admitted. On her first day at the university she meets Richard, who supports her in her struggle to keep up with all requirements in spite of her handicap. They stay together and get married. And though Mary was told she would be infertile due to the chemotherapy treatment – she gives birth to two healthy children. Their - kind of - normal live is completely turned upside down again when 17 years after the first diagnosis a metastatic lesion is found in the pelvic where it cannot be removed without the risk of serious damage and consecutive loss of quality of life. Mary's deep and sincere faith helps her through a devastating and emotionally depressing time in which she tries to prepare herself for the inevitable death, which she can and will not accept at this point: she is only 34 years old and has two little children! And - miraculously – the pain and the disease symptoms disappear and so does the spot on the CT-Scan. She seems to be healed without a new treatment course.

Her truly unique story was written jointly by her and a journalist from the Daily Mirror and is a poignant testimony of the life and faith struggle of a young person with cancer.

Gerlind Bode

Sarah Marston

Sarah – A six-year-old who is unafraid of cancer



This moving story of Sarah' treatment for brain tumor is published in a small brochure illustrated with numerous photos. It is full of courage and hope and could a good companion for the newly diagnosed.

The brochure can be obtained from the National Childhood Cancer foundation, 440 E. Huntington Drive, 4th Floor, Arcadia, CA 91006 (Email: rweaver@nccf.org).

The Marston-Family has started a foundation to raise awareness and funds for pediatric cancer research. More infos: www.summitfoundation.com

Gerlind Bode

New release

Ronald T. Brown (Editor)

Childhood Cancer and Sickle Cell Disease

- A Biopsychosocial Approach -

Oxford University Press, 2006

This comprehensive handbook includes a chapter on childhood cancer: "A prospective and Retrospective View of Pediatric hematology/Oncology" by John J. Spinetta, Guiseppe Masera and Momcilo Jankovic

Letter to the editors

Thank you very much for your newsletter.

It is very fruitful and I like the article " Necessity of Support for Young Adult Survivors". I hope in future there will be more people to share the experiences of carry out support group and how to facilitate the long-term support among survivors or young people who suffer cancer.

Best wishes, Brenda Chan
Little Life Warrior Society
Hong Kong SAR

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