

ICCCPO



International Confederation of Childhood Cancer Parent Organizations

ICCCPO
Newsletter

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A word by the Editor(s)

At every General Assembly Meeting, we have the duty and opportunity to have one half of the board members up for (re-)election. This has given the board the possibility to have, at a regular cycle, new members enter with their perspectives and ideas while at the same time keeping the necessary stability and consistency needed for good reliable work. It is a very democratic rotating system that has worked very well over the years.

As one of the very few members still left over from the very beginning, it was a natural process and time for me to step back into the second row - to have another generation grow into the responsibilities we have prepared for them. As much as this was a rational decision for me, it was emotionally a very hard one to make, as I personally can look back upon a number of very intense working years with a group of people that have become very good friends and whom I would not like to miss. But, as I will still be involved in the well fare of this organization as one of the editors of this newsletter, I am not out of the picture yet.

However, while our organization is growing every year with plenty of new members, it also seems appropriate for me as one of the founding members at this point in time to

give a brief overview of its history - realizing that many people cannot be aware of it:

When we (the German group) started in 1992 with the SIOP meeting in Hannover (Germany) to invite people from organizations similar to ours in Germany, we did not know yet that this was the onset for an international group of parents of children with cancer. We simply had wanted to get together and talk about what was our common interest. I do not quite remember how many groups were present in Hannover, but there were certainly a lot of people in the room - parents, doctors, psychologists, who showed much interest in this sharing. It was still a relatively informal setting (briefly mentioned with only a paragraph in the program), with a couple of presentations from several countries such as Sweden, Italy and Holland. We brought our informative materials with us and invited each other to steal the ideas if they were good and worked. It was then that the Danish group introduced the little booklet "**Chemo Kasper and his fight against the cancer cells**" (*Danish: "Kemomanden Kasper" to us*). The simple, yet working story was quickly adapted by many other groups and got translated into so many languages by now - one of the very easy ways of sharing ideas.

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A word by the Editor(s) cont'd

The idea of forming an international body was in the air, and the Spanish group invited everyone for an international meeting in Valencia (Spain) in spring of 1993 where they had already prepared a set of statutes for such an organization. However, meeting as an international group and working together are two separate things - and as easy as the first one is, the second issue is a lot harder. It took some time to find a common language for the rules and regulations of an international working group until they could officially be ratified in spring of 1994 in Valencia. Eighteen member nations signed the statutes and elected a board consisting of nine representatives, chaired by Jesús Maria Gonzales Marin from Spain.

The early request for two major meetings each year - one in spring for the General Assembly Meeting and one combined with SIOP, the international pediatric oncology meeting, could not be carried out over a long time as it became clear that it would be much too costly for every participating organization (let alone for ICCCPPO itself which has only very little funds). Thus it was decided in 1997 to concentrate on only one meeting per year, which should combine the AGA with the meeting at SIOP. As we realized the impact we could make on the group of physicians, nurses and psychologists attending SIOP, it became clear that this would be our place. In turn, for all parent members it is a great opportunity to take part in the scientific program offered by the professionals and thus be in close contact with the caregivers of their children.

Over the years (and with some tough lobbying on our side) the SIOP board has recognized the importance of the parents' input at their meetings and we are very happy now to see that this is acknowledged in all respects, e.g. we are given room and time for our sessions which have become largely shared sessions with the other professionals.

Again due to our financial resources it became necessary, however, to compromise in those situations where SIOP meets in very remote places - remote to the present majority of our members who are located in Europe and North America - such as Japan in 1998 or Australia in 2001. We decided to arrange our General Assembly meeting in a central European setting (thus we met in Frankfurt in 1998 and will meet in Luxembourg in 2001). At the same time, we will send a delegation of board members to be present at the SIOP meeting in those far away countries. This offers a very good opportunity for parent organizations in that particular part of the world to get together more easily. The success of the meeting in Yokohama insures us that this setup will work as well for Brisbane, Australia.

And most likely, as the membership is growing, we might have to change these arrangements again to meet the needs of all organizations in the future. As we always say: We are flexible ...

Gerlind Bode

Announcements

ICCCPO General Assembly Meeting and Conference

September 6-9, 2001 in Luxembourg. Arrival: Tuesday evening. Departure: Sunday afternoon. There will also be a joint meeting of long term survivors, their siblings and friends (age 16 and more). Program and more details will follow soon. Contact: Marianne Naafs or Gerlind Bode (see addresses)

SIOP meeting in Brisbane

Oct. 10-13, 2001. There will be a (regional) parent meeting organized by Australian parents and by Simon Lala (for more information see addresses)

The 2nd International Conference on Cancer and the Adolescent

March 5-6, 2001 at the Royal College of Physicians, London. Speakers from: Canada, United Kingdom and the United States. Sessions on: Epidemiology, Units and their problems, Young People and their Families, Specific Cancers and Ethics.

Contact: Teenage Cancer Trust
Samantha Greshoff Conferences
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International Conference on Psychosocial Support Strategies for Children with Serious Illness

May 24-25, 2001 at Barretstown Castle, Co. Kildare, Ireland.

For more information contact:
The Haugton Institute
St. James Hospital, Dublin 8,
Ireland

Letter from the Chair

On behalf on the Executive Committee, we want to thank those who were present at the ICCCPPO meeting in Amsterdam. Over 125 parent representatives from 42 countries met for three days and learned from informative lectures, posters and workshops. They shared their experiences, renewed friendships and made new contacts. We will publish some of the outcomes and presentations of the conference in the newsletter to inform those who could not attend.



*Marianne C. Naafs-Wilstra,
Chair ICCCPPO*

The General Assembly ratified the application of 11 new member organizations (eight full and three associate), which brought our membership to 53 organizations from 43 countries.

Gerlind Bode felt it was time for her to give up her seat in the Executive Committee. Gerlind is the one who stood at the

very beginning of the international confederation. In 1992, on the occasion of the SIOP in Hannover, Germany, she invited parent groups from several countries in Europe. That is how it all began.

We can't thank Gerlind enough for the tremendous work she has done over the years. She organized several international parent meetings, most of them

by "remote control" (Paris, Montevideo, Istanbul, Vienna), has been editor of the newsletter and supported ICCCPPO with her expertise as a networker between parent groups and physicians from all over the world. Her contacts have been very valuable for ICCCPPO. We are very happy that we will not lose Gerlind. She will stay committed to ICCCPPO by remaining on the newsletter committee.

The Executive Committee welcomed a new and enthusiastic member on the board, Geoff Thaxter of the National Association of Childhood Cancer Parent Organizations (NACCPPO), from the United Kingdom.

The Annual Report 1999-2000 will not be included in the newsletter but can be obtained from the secretariat. It gives an impression of the various activities of ICCCPPO. It goes without saying that the Executive Committee cannot do all the work by itself. The support of the Secretariat in Canada is tremendous. But there remains a lot to be done, for which we need your help, input and ideas. The Confederation is not the Executive Committee - but you, the members. Write, e-mail, fax us, tell us about your successes, your problems, your needs. This newsletter, and hopefully very soon, our website, are both great media to share - so go ahead and use them. Also try to keep in touch with other member organizations. If you would like to receive a list of e-mail addresses, please contact the Secretariat in Canada. Together we can make a change!

Marianne C. Naafs-Wilstra, Chair ICCCPPO

Membership fee and Solidarity

As you may well know, the ICCCPPO membership fee is \$500 US per year per nation. This means that, if there is more than one organisation in your country, you can split the fee. You will also have to decide who will vote at the General Assembly for your country, because the ICCCPPO bylaws say: one country, one fee, one vote. There are organisations from less wealthy nations that can't afford to pay the full fee. Therefore, we created the possibility to apply for a reduced fee.

At the same time, we make a strong appeal to our wealthy member nations and organisations to support other members by paying their annual fee. Some countries - Italy, The Netherlands - already pay for others, thus making it possible for them to be an active member of the Confederation and to retain their voting right. We trust we can count on you! Solidarity is and will remain a key word in an organisation like ours.

Marianne Naafs

Introduction

The development of pediatric oncology (PO) starts with the establishment of a pediatric cancer unit (PCU), a referral center for a pediatric population of one to several millions. The PCU is the heart of a local PO network consisting, besides the PCU, of peripheral satellites cooperating closely with the PCU, a "triage" system at the "front" and a transport system for good risk patients. In addition to this local network, a national network will be developed to coordinate the local networks and to defend the interests of children with cancer and their families. Parents' organizations play an important role in both networks.

Status of Pediatric Oncology in different countries

In very poor countries PO has no priority. With decreasing mortality rates (cumulative risk to die during the first five years of life <10%), cancer emerges as a leading cause of death in children over five years of age. Within the same country, cultural and socioeconomic differences influence the access to care: the biggest obstacle is poverty which is always associated with lack of education, poor hygiene and unemployment. Parents who understand that childhood cancer is curable in 3 out of 4 patients, but who are too poor to pay for an adequate treatment, suffer the most.

Motifs to start a Parents' Organization

Destitution, despair and bitterness are important motifs for parents, families and friends of children with cancer to cooperate. It may help parents to learn what others have done to cope with practical and emotional difficulties: where to stay; buy drugs and food; what to say to the child, siblings, grandparents and teachers; how to speak to doctors and nurses. Lack of competent, comprehensible and comprehensive information or insufficient palliative care and, of course, the desire to do something for the deceased child are other strong motifs.

Who initiates a Parent's Organization?

In Yogyakarta (Indonesia), parents of surviving leukemic children were the promoters of a Parent Association of Leukemia Children. In Jakarta, the Indonesian Childhood Cancer Foundation was initiated with the goal to offer Indonesian children with cancer the same chances Dutch children have. At the Johannesburg Hospital in South Africa, energetic catalysts were needed to bring up the parents association of the Children's Hematology and Oncology Clinics that spread over the whole country. In Recife (Northern Brazil), a psychologist and the head of a division of PO initiated in 1985, a center offering housing and other support to parents of children with cancer coming from far. In Romania, an organization set up by despairing parents in 1996, is providing housing, drugs, medical and practical information and for the poorest - clothes, shoes and sometimes food.

What are the goals of Young Parents' Organizations?

Besides providing shelter, drugs and transportation, parents' organizations, by forming therapeutic alliances with the hospital staff, can help the parents and patients to understand the disease and to actively participate in the treatment; they can assist in the difficult transition from curative to palliative treatment and advise families after the death of their child. Parents' organizations can do a lot for the patient and his/her siblings: they can assist in training, organize babysitting, camps, theaters and can provide, for older patients, individualized help to obtain optimum professional formation. Parents' organizations play a pivotal role in advertising that cancer is curable and that the majority of survivors are to be considered as normal, with a normal working capacity and life expectancy. On the national level representatives

can, by cooperating with other parents' groups, lobby for the interests of children with cancer, by demonstrating for example that to treat good risk cancer patients may not cost more than to treat other diseases. Parents' groups can contribute to the formation of PO specialists (medical and non-medical) and help to finance staff positions.

When should Parents' Groups be set up?

As soon as PO activities start at a PCU, it is time to set up a parents' organization to support the parents of recently diagnosed children with cancer, but also to assist the PCU in its daily activities. It is important that there is close cooperation between the hospital staff and the parents' organization. If the PO structures get more complicated, specialized parents' groups may be formed, according to the needs of children with cancer in a given country.

Pitfalls

If parents' organizations comprise only parents they may lack stability. It may therefore be wise to include

motivated volunteers and to encourage them to become active members, according to their special skills and know-how. In order to become efficient, parents' groups must be structured and have bylaws. They may cooperate with other organizations that support children with cancer, e.g. Cancer Leagues, Support Groups for Chronically Ill Children, Child Health Institutes, National and International Governmental and Non-Governmental Institutions such as WHO, UICC, INCTR etc. In order to avoid pitfalls, twinning of well established and new parents' organizations might be helpful.

Discussion from the floor

In Alexandria (Egypt), physicians have successfully initiated parents' organizations. For well-conceived projects, more sponsors are available than anticipated.

(The PODC Committee of SIOP at the 32nd SIOP Congress in Amsterdam, October 5, 2000.)

Miscellaneous

Chemo-Kasper Goes

International: The little booklet, **The Chemo-Kasper** - originated in Denmark - is now translated into these languages and available at the different parent initiatives of those countries, except for those set in ().

Danish / Dutch
Estonian (Germany)
German
French (Switzerland)
Icelandic / Italian
Latvian (Germany)
Lithuanian (Germany)
Norwegian / Portuguese
Romanian / Russian
Spanish / Swedish

Radio Robby is available in the following languages: Dutch, German, Portuguese. Do you know of any more? If so, let us know.

Now available from the Secretariat:

- ICCCPPO Bibliography, an annotated resource list of all publications by parent groups
- Handouts of the various workshops
- SIOP Guidelines for the organization of a Pediatric Oncology Unit and European Charter Child in Hospital
- SIOP Psychosocial Guidelines, written by SIOP together with ICCCPPO members (education, communication at diagnosis, therapeutic alliance, long term survivors, siblings, terminally ill children)

To keep the costs low, we prefer to mail these publications by e-mail.

Matthew's World: At the SIOP Opening Ceremony "NKT Theaterproducties" performed the musical **Matthew's World**. NKT is a theater company comprised of young people who, under the leadership of experienced theater makers, perform successful family productions, most of which have a social theme. The theme of Matthew's world is "the forgotten child". All the songs from the musicals of NKT have been released on music cassette or compact disc in Dutch and English.

For information: NKT Theaterproducties, Ged. Singelgracht 16
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Tel: (31) (299) 434325, Fax: (31) (229) 435297
Email: nkt@worldonline.nl

An Open Letter ... to a parent with a child newly diagnosed with a life threatening illness

You have just started into one of the periods of your life that you will always remember. You never thought that something like this could happen to your child.

You thought that it was your right that your child would grow up to be just like you, with the occasional illness or broken limb, but you never anticipated an illness that could take his/her life. Now you know differently, and if you are like most of us who have been down this path ahead of you, then your outlook on life will probably be changed forever from this week onwards.

During the next few weeks you will go through many emotions:

- You will feel anger at the unfairness of it;
- You will grieve that all of the dreams you had for your child could come to nothing;
- You will try to bargain with God to cure your child;
- You will blame yourself for causing the illness;
- You will regret not doing things with your child that you intended to;
- You will feel lost and confused by lots of medical jargon and new words;
- You will agonize over what you should tell your children, your parents, your friends;
- And you will wonder how you will cope with it all.

In other words, you will behave just like all the rest of us parents who have been in your situation.

You will have to develop your own methods for coping with things, depending on your own personal situation. However you may find a few guidelines useful as a starting point:

- Be honest and open about the illness, to your relations and friends, to the school, your employers, but most of all to yourselves and to your children. Your children will know that they are ill; don't make them hide their feelings to try to protect you.
- Your family and friends will not at first know what to say to you, and they will be very uncomfortable with you. The more openly you talk about things, the easier it will be for them to respond to you and give you the help that you will need so much in the coming months.
- Get used to saying the name of the illness out loud. Words like cancer and leukemia are normally only spoken in hushed voices, and never in the presence of someone who has them. It will be with you for a long

time, so get used to saying it, and even to talk about death. It makes it much easier for all of your family and friends to talk openly if you do so.

- Don't be ashamed to feel or show emotion; it just shows that you are human. If you didn't feel angry, sad, confused, and many other emotions, when you learned of the diagnosis, then you are very unusual. Don't forget that your sick child, and your other children, will have to cope with many new experiences and emotions. Let them see that its all right to feel afraid, to be unsure, to cry at times.
- Remember that you are in this as a family. Many families, who have a good marriage to start with, find that they are all strengthened by the experience; but it is not unusual for a marriage to be very stressed by all the extra demands that an illness like this will put on it.
- Call on all the resources that you have. Use your family and friends; if they are true friends they will be only too glad to help you now that you really need them. Use your church; get people to pray for you and your child. You will be surprised how much and how readily people will open up and help you, if only they know how; and that is why you need to make your needs known.
- There are no guarantees. The medical staff will do their best; there may be a very good prognosis for your child; but it is still a life threatening illness, and you will live with this for a long time.
- Don't be afraid to ask the medical staff. You will probably not take in half of what is said in the early discussions, and there will be a whole new vocabulary in your life. Keep notes of the questions you want to ask. There is a lot of literature about, and you will want to get as much knowledge as possible, so ask the staff what they recommend.
- There will be times when all seems very dark, and some very happy times. The best way to get through the coming weeks and months is to take it one day at a time. May you find the strength in yourself, your family and your friends to grow through this trying time in your lives.

From other parents who have been there before you.

Julian Cutland



Left: An informal meeting at the conference.

Right: Marianne Naafs-Wilstra, chair of the ICCCPO.



Left: The international buffet was enjoyed by all.

Below: Visitors came from all over the world to attend the meeting.

A look at the Amsterdam conference...



Above: Sophie Broers and Juanne Nancarro Clarke reading from "Spinach and Raisins for Lunch".

Below: Attentive listeners during a seminar.



The new board



From left to right: Mokhtar el Harras, Geoff Thaxter, Rogelio Araujo, Simon Lala, Marianne Naafs-Wilstra, Sadie Cutland, Christine Wandzura and Mark Chesler

Thoughts of a Greek long-term survivor

My name is **Spyridoula Christoforou**, I am from Greece and I am a long-term survivor. I got sick with acute lymphoblastic leukemia at the age of three in 1985. I was subjected to medical treatment for five years. At the time being, I am cured. But I always live with the fear of getting sick again. The Busulfan Cortisone I had to get and the radiotherapy caused thyroid and skin problems later. But except for that I lead a healthy life and have no serious health problems to face. I live a normal life with my family and my friends.

Unfortunately, what I never experienced was childhood. When the doctor diagnosed my illness, I was just a little girl, I couldn't understand the seriousness of my situation, but I felt that I had to lead a completely different life from all the other kids of my age. I was not allowed to eat salted food, it was forbidden to me to get tired and to stay in the sun. Even playing outside was out, because I had to be every week, and sometimes every day, at hospital. Sometimes when I try to remember those days, I feel that I grew up quickly. At the age of four or five I had to cooperate with the doctors, to come up with my problems and to discipline myself - for my own good - while all the other children could enjoy the best years of their lives.

After having a very positive relationship with the medical group that was responsible for my treatment, I was encouraged by them to become an active member of FLOGA, the Greek parents association of children with neoplastic

diseases. I joined the Association in 1999. My main intention is to come in contact with children who suffer from these diseases, and their parents and to encourage them to face their problems. For that reason I collaborate with the psychologist of the children's hospital.

I realized that children really liked my presence near them. They kept on asking me about the treatment and about my life nowadays. Some of them compared their situation with mine. Playing with them helped them to express their feelings and fears. It sounds strange, but how could an adult address such a child who fights for his life day by day, hour by hour? Should he treat him like a child or like an adult? Actually, I had to deal with mature children who were injured by life.

As for their parents, they kept asking me if their child could ever become as healthy as I am. They were interested to hear about my situation and some of them expressed their worries about their child's future. For them I was an example, a very good and helpful example. Both children and their parents were asking me if I would visit them again soon. When I look into their eyes, I feel that I am in their shoes. I would like to tell the people that we, the survivors, can really help children and their parents to cope with their sickness. Children need someone who has faced the same problems, who can share their worries and fears. I am sure that when they see us, they wonder if they ever become as healthy as we (survivors) are.

As for their parents, we are a proof of what the doctors tell them about the prognosis of the disease. In cooperation with the psychologists and the doctors of the clinic, we can make children understand the seriousness of their situation and help them express their feelings especially if we are close to their age.

Unfortunately, in Greece there is no such volunteerism on the part of the survivors. Most of them want to forget the past. That's really sad, because if they do so, then they forget who they are and what they can offer to society.

All of us must come in contact and create a team available to stand by those children. As I have heard in some European countries, such teams visit families who have children with cancer at home, they talk with them and offer them encouragement.

The Greek medical system lacks psychological support. There are only a few persons who work as psychologists with those children. Survivors could offer a lot in that section.

To conclude, I would like to thank the newsletter for giving me the opportunity to express my thoughts and feelings.

Childhood cancer is a problem that becomes more and more serious and for that reason the survivors' contribution is very important.

Spyridoula Christoforou
Email: gzech200@yahoo.com

Themes and Variations - *the subtitle of this year's SIOP program*

Introduction to this year's ICCPO meeting at the SIOP conference in Amsterdam by the SIOP chairman, Prof. Dr. Günter Henze

The theme is: our efforts towards the child - not only the child, but the child suffering from life-threatening disease, from cancer.

One could also say: The theme is cancer. But as true physicians we would not be satisfied by saying: we are treating cancer.

We have the ambition not to treat the disease but to treat patients as individuals suffering from a disease, and this makes a big difference.

We are also aiming at curing patients and not only diseases. Children cured from cancer should be able to live a normal life, have families and have - if possible - a normal life expectancy.

So, the theme is the child. What are the variations?

The variations, for instance, are the different conditions under which the children live and can or cannot be treated. The differences between the conditions are considerable.

In May 2000, I attended the regional meeting of SIOP Africa organized together with CHOC, the South African parent organization. Hans-Peter Wagner, the chairman of the SIOP-committee PODC, was also there and presented figures about access to treatment. In the developing, or if you prefer the term,

emerging countries, only about 15% of children have access to modern treatment which offers the option of cure. Many of the affected children are never seen by a doctor and die, undiagnosed and untreated.

In September, just a few weeks ago, we celebrated in Germany the 20th anniversary of the foundation of the German leukemia research aid. This was for me the opportunity to give a review of what has been achieved in our country with the help of parents. With their help we were able to improve the conditions for treatment, care and research dramatically.

Here we have again variations of the theme.

Variations mean that we are dealing with a spectrum of variables and that - like a composer - we have the opportunity and the power to put the variables together according to our needs and imaginations. This can be a process - and will be a process - that takes time. But if we combine our efforts, "Parents and Physicians against Childhood Cancer", we will be able to improve the variable conditions for our children which are at present still far from satisfactory for the majority world wide.

Let us be composers: We all know the theme and everybody should make his contribution in creating variations to the benefit of children with cancer.

Prof. Günter Henze,
President of SIOP
Chief of Pediatric Oncology, Charité, Berlin (Germany)

International Year of Volunteers 2001

The United Nations General Assembly proclaimed the year 2001 as the **International Year of the Volunteers (IYV)**. This global recognition will allow countries the unique opportunity to highlight the achievements of generous and caring citizens.

We encourage every group to consult the following website for updates: International Year of Volunteers: www.iyv2001.org



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