

ICCCPO

International Confederation of Childhood Cancer Parent Organizations



1994 10th Anniversary
2004 ■ ■ ■ ■ ■ ■ ■ ■ ■ ■



ICCCPO-Anniversary booklet

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Once upon a time, there were four people named Everybody, Somebody, Anybody and Nobody. There was an important job to be done, and Everybody was sure that Somebody would do it. Anybody could have done it, but Nobody did. Somebody got angry about that, because it was Everybody's job. Everybody thought that Anybody could do it, but Nobody realized that Somebody wouldn't do it. It ended up that Everybody blamed Somebody when Nobody did what Anybody could have done.

Anonymous

Commemorating Ten Years of ICCCPPO

As the newly elected Chairman of the International Confederation of Childhood Cancer Parent Organizations, it's a pleasure to report on the current status of the organisation and its plans for the immediate future.



Simon Lala
(New Zealand)
Chairman

From its humble beginnings, ICCCPPO can be proud of its continually growing membership. As of the last Annual General Assembly, there were 61 parent groups from 52 countries. Moreover, the executive board is representative of all parts of the world which ensures the diverse needs and issues facing parent groups are being heard and addressed where practical.

One of the measures of ICCCPPO's success has been the programs that have been established. These include the quarterly newsletter, the Annual Parents Conferences, the Stipends Program, the Parents Helping Parents Fund, the International Childhood Cancer Day, the ICCCPPO website and the Resource library. All of these programs have helped our members gain valuable information and support from each other.

The Health Professionals are an integral partner for ICCCPPO. We have a wonderful working relationship with the International Society for Pediatric Oncologists (SIOP) and we thank them for respecting and acknowledging the voice of parents in the treatment of Childhood Cancer.

Like many voluntary organizations, ICCCPPO receives no governmental funding and relies on membership fees and sponsorships to be able to deliver its programs. ICCCPPO acknowledges the sponsorships received from Amgen Corporation which provided the initial funding for ICCCPPO to become established, the Cancer Research-UK support of the ICCD (International Childhood Cancer Day) and CLIC (Challenging Cancer and Leukaemia in Childhood) supporting our recent conference in Dublin. We will always gratefully welcome new sponsorship if it means being able to help children suffering from cancer.

The voluntary time and money spent by board members in attending Board meetings and undertaking the tasks of running the organization must not be underestimated. Volunteer services have been estimated at around USD 50,000 a year. My thanks go to all past and current board members for their contribution and dedication.

A special thank you goes to our two life members, namely Jesús Maria Gonzales Marín (Spain) and Gerlind Bode (Germany). The contribution by these two individuals has been extraordinary, and we welcome their continued support.

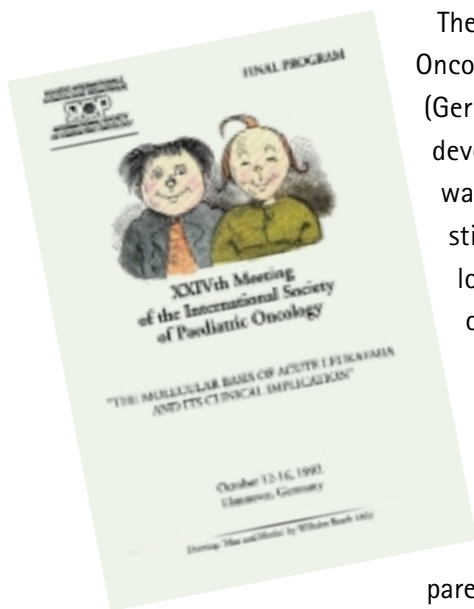
Looking ahead there are many challenges. The Board is committed to delivering more of the same programs that are currently in place. As funds permit we will endeavor to look at implementing new programs. These would include: establishing a more robust international survivors network and addressing the issues facing the increasing number of survivors. Development of regional committees and delivery of regional conferences would also go along in addressing the concerns facing specific regions. We have a strong commitment to working with the United Nations to ultimately ensuring every child suffering from cancer can get access to treatment.

In closing I am looking forward to the challenge of building on the work of my predecessors and making a difference to the lives of children suffering from cancer wherever they may be. I take this opportunity of also thanking all our members for their outstanding work and their participation in the journey towards achieving ICCPO's mission.

A handwritten signature in blue ink, appearing to be 'M. Bode', is centered on the page.

How it all began ...

The Story of the international parent group for the benefit of children with cancer



The annual meeting of the International Society of Pediatric Oncologist (SIOP) in October 1992 took place in Hannover (Germany). For the first time many young doctors from developing countries were invited to participate; their stay was made possible by travel stipends. Most of these stipends were provided by German parent groups (on the local and the national level). This seemed to be a good opportunity to attach an informal parent meeting to the official scientific meeting.

We, that is the German Leukemia Foundation, the umbrella-group of all German parent initiatives for children with cancer (at that time chaired by Ulrike Baum from Hannover) invited representatives from parent groups in Europe or elsewhere for a first get-together, an exchange of ideas and experiences. In the early 1990's parent groups were well established in Middle Europe as well as North America. Their work was accepted as indispensable on pediatric oncology wards. All groups could report about a number of well established programs. Those of us who were involved in this meeting may still remember the excitement of this possibility to reach across the borders and to realize that there were very similar problems everywhere, for which some groups could offer practical "remedies".

Group representatives from Austria, Bulgaria, Finland, Germany, Holland, Norway, Italy, Poland, Spain, Sweden, Switzerland and the USA were present – all in all 45 people. We had managed to set up our own program in the midst of a medical scientific meeting – thus demonstrating the importance of parent involvement. Physicians and other professionals came to sit in and listen, some with genuine interest (especially from former East Block countries, who were trying to initiate parent groups in their own hospitals), others with sceptical doubts, uneasy about this group of people: what was their intention? What, if they rocked the boat?

1992

timeline

Ulrike Baum addressed all participants of the SIOP conference in the opening ceremony on behalf of the parents, thus creating a stronger awareness of their presence (a welcome speech at the SIOP opening ceremony by the parent representative has become a tradition ever since). Very supportive and encouraging was not only Prof. Riehm, the host of this SIOP meeting, who officially acknowledged the presence of parent representatives among the delegates, but also Prof. Wilbur from San Francisco. He presented himself in the double role as a physician and a father of a child with cancer and strongly supported the importance of the role of parents in hospital.

We were not finished with the intense discussions by the official end of the time assigned for formal presentations, thus we had to find another room where we could continue. There was so much to share – from insurance problems to housing facilities, information brochures or fundraising ideas ... and it became obvious that meetings like this should be called for on a regular basis. The invitation of the Spanish group from Valencia seemed a good opportunity to call for a next meeting in May 1993.

We exchanged our booklets, giving each other permission to translate those relevant for the use in our own countries. Here the little Danish picture book "The Chemo Kasper" started to become "international". It got rapidly translated into Dutch, German, Norwegian and Swedish – and is now available in two dozen different languages.

By the end of the day we agreed to keep in close contact by way of a newsletter (designated editors: Marianne Naafs-Wilstra and Gerlind Bode). Those who attended the following days of the SIOP conference were approached by many physicians who handed out their cards and expressed their wishes to connect with parents in their country.





Gerlind Bode
(Germany)

Valencia is a very beautiful city, particularly in Spring. Unfortunately, the international delegates from numerous parent groups did not see much of it as they were actively working to establish an international body of parent initiatives for children with cancer. Along with a conference on medical and psychosocial issues of pediatric oncology (the first international conference of this kind in Spain – organized by the Spanish Confederation, seated at that time in Valencia), the international delegation was asked to work on statutes that could unite all common interests. Delegates from at least 16 different countries (such as Brazil, Bulgaria, Canada, Finland, Germany, Holland, Italy, Norway, Poland, Portugal, Russia, Spain,

23 - 25 April 1993: Valencia, Spain

Switzerland, Sweden, Venezuela and the United States of America) were present and busily worked on phrasing and rephrasing paragraphs. However, it turned out to be not an easy task at all, since the representatives from different countries could not agree on common legal terms. Long and elaborate discussions did not bring us any further. The task had to be postponed. In a written agreement signed by all delegates, it was agreed to take this task home to the board of each country organization, to cooperate in working groups (such as the North-American group, a middle and a northern European Alliance) and come back after one year to finalize the issue. The delegates also signed a declaration that they would promote the right to treatment for all children with cancer all over the world, the co-called Valencia Declaration.

The educational program organized by the Spanish Confederation was very interesting for all participants and clearly demonstrated the many different issues parents of children with cancer are involved in and stimulated active contributions. Discussions continued even during the social gathering in the evening.



The first international conference of the Spanish parent association hosted a first congregation of parent-representatives from numerous countries with the aim to form an international body.

1993

5 - 9 October 1993: San Francisco, USA

The SIOP meeting in San Francisco gave us the next opportunity to meet and continue to work on the statutes for the international body. Though no real progress in a commonly acceptable paper could be made, more than ever the wish for a united group was voiced. Even finding an acceptable name was not easy and could not be completed here. It was important to the founders to demonstrate that this group was a confederation of parent initiatives with parents of children with cancer actively involved – as opposed to fundraising organizations (usually set up by professionals).

A special program for parents and survivors during the San Francisco SIOP meeting under the heading: "Childhood cancer – a family affair" continued the "tradition" started in Hannover the year before.



All children with cancer should be given a chance to be cured

When in 1994 representatives from organizations from 16 countries were signing the Constitutional Act that initiated the way of ICCCP, we wished that the idea that has moved us, would be developed and extended to the possible biggest number of countries.



Jesús M.
González Marín
(Spain)
Chairman from
1994 to 1995

Today, 10 years later, the reality has overcome our dreams, at least mine, and 52 countries that constitute our Confederation and the current composition from the Executive Board give an exact idea of the world-wide extent we have reached.

I had the honour and privilege, and I will have it as long as I live, to have been elected the first Chairman of ICCCP. And there were people who asked me about what was the impulse to summon so many organizations in Valencia and convince them of the need of our union. Possibly due to my linguistic limitations, I speak only Spanish, my answers were very poor. In this booklet I want to repeat:

It was easy to create ICCCP because all the people had the same ideas and we were moved by the same feelings and we explained them in the "Declaración de Valencia en favor de todos los niños enfermos de cáncer del mundo" (the Bill of Valencia in favour of all children with cancer in the world). Our purpose was and continues to be that all children stricken by cancer around the world would be given the same diagnostic and therapeutic possibilities.

1994 . . .

We, the mothers and fathers of pediatric cancer patients who have the right and the duty to fight for our children's lives cannot do this alone. Though it would be difficult to stop all of us, joined in a common struggle, we need the generosity and the support of all the people around us, indeed, working with energy, illusion and ceaselessly, in order to demonstrate that we are first in maintaining that fight, each and every one of us.

Wherever you live, to find out that your child has cancer is hard and painful for the parents too. Those of us who live in countries with all possibilities have the moral responsibility and the moral duty to help those in poor countries, with our experience and our access of information and if possible also with economic support so they can reach the best level of a developed organization and to be as effective as possible in their fight, that is everybody's fight.

I would like to express all my affection and gratitude to the people who constituted the first executive board for their excellent work and their patience with me, special thanks to Jim, Barbro, Pia, Gerlind, Antonio, Olga, Marianne and Kurt and my recognition and solidarity to all the people who have been and are part of all the executives boards that have been created and show the solidity and the correct trajectory of the ICCCPO, our Universal Confederation.





Delegates work hard on the wording of the statutes.

Delegates from more than 20 countries came prepared with their papers and hundreds of arguments to this meeting, which was supposed to be the inauguration of the international organization of parent initiatives. Many hours of tough work were still to follow before the group could agree upon the name (International Confederation of Childhood Cancer Parents organizations = ICCCPPO) and a version of the statutes which had to be in accordance with the Spanish as well as international law. The founding members from Italy, Poland, USA, Brazil,

28 April - 1 May 1994: Valencia, Spain

Holland, Germany, Denmark, Norway, Venezuela, Portugal, Greece, Canada, Spain, Sweden, Finland and Switzerland signed the articles of the confederation in an official act at the Town Hall under the auspice of the Mayor of Valencia and several delegates from the Spanish state government. They agreed upon the following Mission Statement:

"To share information and experience in order to improve access to the best possible care for children with cancer everywhere in the world"

The host and initiator of the meeting, Jesús M. Gonzales Marín, became the first president of this organization, and members from Denmark (Kurt Hansen), Germany (Gerlind Bode), Holland (Marianne Naafs-Wilstra), Italy (Pia Bonini), Portugal (Prof. Dr. António Gentil Martins), Barbro Erikson (Sweden) and Olga Ramirez (Venezuela) made up the first board. Sweden offered to host and finance the secretariat for the first years, thus Barbro Erikson from the Swedish Barncancerfonden organized the secretariat and had to arrange for stationery as well as a bank account. All members were asked to think of a logo for this new group. The assembly voted for two official meetings per year: one in Spring and one attached to the SIOP meeting. The General Assembly should convene each year in Spring.

Celebrating the launching of ICCCPPO at the Valencia Town Hall





20 - 24 September 1994: Paris, France

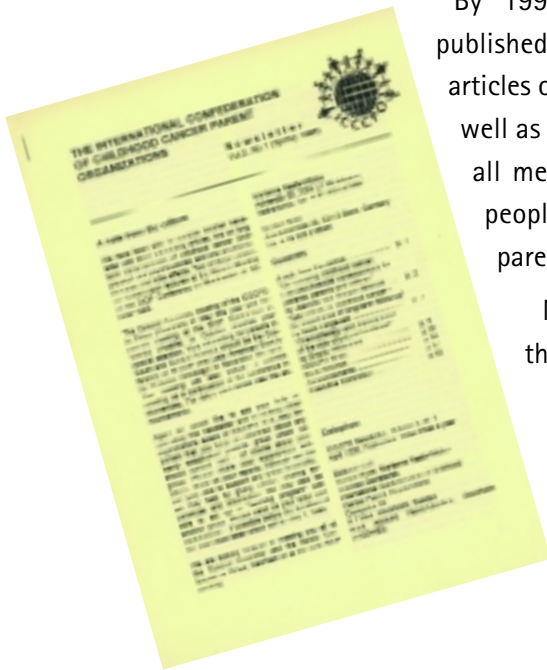
This SIOP meeting was used to raise awareness among all participants of the scientific conference, especially the physicians, for the international group of parents. Pamphlets about the prospective programs of ICCCPPO were distributed and contacts to the SIOP board were initiated. The ICCCPPO board could agree on a logo which represents the unity of families of children with cancer in the whole world.

Newsletter

By 1994 the ICCCPPO-newsletter was established and being published twice to three times per year. It always includes several articles of interest for parents and patients, news and information as well as announcements for upcoming events. It gets distributed to all member organisations free of charge and reaches plenty of people interested in ICCCPPO business, professionals as well as parents – the first real service ICCCPPO could offer its members.

Many issues have been translated into Spanish thanks to the help of Hortensia Díaz Asper (Madrid).

Today, the newsletter is published three times per year, gets distributed to approx. 1000 addresses all over the world in a printed as well as digital version and can be downloaded from the ICCCPPO- website www.icccpo.org



www.icccpo.org

1994



The newly elected board
 Front: Marianne Naafs-Wilstra, Christine Wandzura, Sadie Cutland
 Back: Pia Bonini, Kurt Hansen, Gerlind Bode, Barbro Erikson, Mark Chesler

The 25th anniversary of the Candlelighters USA was a perfect opportunity to combine an educational conference with a meeting of the international group and to hold the next General Assembly. The conference offered many lectures on different topics of childhood cancer and parent involvement. Special highlights were the visit to the White House and a candles lighting ceremony on Capitol Hill supported by representatives of the US Senate.

12 - 16 July 1995: Washington, USA

The general assembly elected Kurt Hansen (Denmark) as chair and Jim Kitterman (USA) as vice chair. Christine Wandzura (Canada) Mark Chesler (USA), Sadie Cutland (South Africa) and Lupita Alejandre Castillo (Mexico) joined the board. The latter two could contribute from their personal experiences in less privileged countries, which became a valuable assistance for board decisions.

The resigning president, Jesús M. Gonzales, was chosen as the first Honorary Member with respect to his efforts in getting ICCCPD on its feet.

The applications of the first national members were officially approved: Canada, Denmark, Finland, Germany, Holland, Iceland, Italy, Morocco, Portugal, Sweden, Spain, USA.



Candlelight-Walk at Capitol Hill (Washington, D.C.)





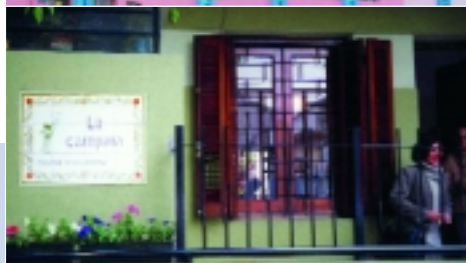
10 - 14 October 1995: Monte Video, Uruguay

It could have become one of the most mysterious meetings as on arrival in Uruguay no one of the board was sure what to expect. Yes, we were assured by the SIOF organizing committee, there would be a parent meeting and many parents from South America were invited. A formal program? Well they (the South Americans) would need to learn so much from others, so let's have an informal meeting with a number of topics, such as "How to set up parent groups," "How parents can help during treatment" and many more.

The hotel in which the congress was supposed to start the next day was still under construction. The room assigned to ICCCPPO could not be inspected (nobody knew how large it was, what kind of equipment would we find ...) We were already sure we would have a small group session among ourselves. And then, what a surprise: the room really existed and filled up with more participants than chairs available (we counted more than 90 names on the attendance list); and a very vivid discussion started. We learned a lot from our host parents about the situation in countries like Uruguay, Brazil, Argentina, etc. A visit to the hospital and the parent house gave insights into the local situation and was an eye-opener for many of us.



A visit to the local hospital and parent house



1995

1996

16 - 19 May 1996 Aarhus, Denmark



Kurt Hansen
(Denmark)
Chairman from
1995 to 1997

A meeting of the International Nordic Conference (meeting of all Scandinavian parent initiatives) ICCCP0 could hold its General Assembly meeting and admitted seven new members from the following nations: Greece, Latvia, Norway, South Africa, Switzerland and Yugoslavia.

30 September – 3 October 1996: Vienna, Austria

In Vienna, one has to start with a "Heurigen", the fresh, sparkling wine of the most recent harvest. It has an unpredictable effect. But it certainly stimulates group dynamics and an enormous interest for information. Those who had a clear head the next morning were invited to listen to a series of lectures on the quality of life from different perspectives: by the physicians, the psychologists and the parents. Reports on alternative treatment, rehabilitation and parent coping skills were among the topics of the following days. It was the first time that the ICCCP0 program was truly integrated into the official SIOP program.





A board meeting of the "other kind"

20 - 23 May 1997: Johannesburg, South Africa

The first African meeting for parents and professionals involved in the care of children with cancer called for by CHOC, the cancer parent group at the Johannesburg hospital, provided the background for a joint meeting on the international level. The ICCCP board had an extended meeting prior to the AGA (in one of the most spectacular bush resorts) and had decided to propose some changes to the general assembly such as holding only one meeting per year which should coincide with the SIOP conference and to arrange for the AGA at that meeting. It had become obvious that obligations more than once per year would be both too costly and not manageable time-wise. At the same time it was felt that the presence of the parents at the SIOP conferences was very important. Thus ICCCP should make an effort to be integrated there. The board agreed to hold at least one extra meeting (usually in the Spring) to view all proposals, applications, the budget and the projects as well as prepare the decisions to be made by the following general assembly.

The AGA elected Mark Chesler (Candlelighters USA) as Chairman and Marianne Naafs-Wilstra (VOKK, The Netherlands) as Vice-Chair. Johan Sandal (Norway) was newly elected to the board. With the support of the Canadian Candlelighters, the secretariat could be moved from Sweden (who had hosted and financially supported the secretariat over so many years) to Canada, where Eleanor Pask, at that time Executive Director of the Canadian Candlelighters, took upon the job that Barbro Erikson had carried out over the past years.

Five national groups were admitted as new members: Austria, Greece (IASO), Japan, New Zealand, Venezuela and two groups as associate members (from Brazil and the UK).

Africa has much to offer



1997

ICCCPO -

A Growing Organization

I was Chair of ICCCPPO from May 1997 through September 1999. During that time period we achieved two major accomplishments and began two more. The latter two have been realized more successfully in the succeeding years.

Perhaps most importantly, we made an effort to expand ICCCPPO membership, particularly to groups of parents in the less wealthy nations of the world. And in those two years ICCCPPO's membership grew from 18 member groups in 17 different nations to 45 member groups in 39 nations.

Second, we created interactive educational programs at our AGA meetings.

Workshops that drew upon the expertise of our members, and presentations by scholars from SIOP and other organizations (on medical, educational, organizational and fund-raising issues), made our yearly meetings not just social and business affairs, but arenas for member organizations' growth and further development.

In addition, we began work that has come to fruition under the later leadership of Marianne Naafs-Wilstra. For instance:



Mark Chesler
(U.S.A.)
Chairman from
1997 to 1999

We began to tighten our administrative and financial procedures. We moved the Secretariat from Sweden to Canada and developed procedures for accurate billing of member dues, reduced fee arrangements, etc..

We began to develop systematic working relations with SIOP (first the Psychosocial Committee and later the Board) and with the Nurses' Association. Meetings at which SIOP and ICCCPPO colleagues co-presented and worked together were undertaken.

A handwritten signature in blue ink that reads "Mark Chesler". The signature is written in a cursive style with a long, sweeping underline.



Celebrations at the hospital in Istanbul

In spite of communication problems with the local organizing committee of the SIOF conference in Turkey we managed to arrange for an ICCCPPO meeting with local parents of Istanbul. An impressive dinner evening concluded the first day which gave us an insight to the pediatric oncology ward of the major hospital in Istanbul.

At the conference papers from several parent initiatives demonstrated the variety of work done in different areas of the world. The founder of the parent initiative in Japan, Mr. Iwata, was so impressed by the quality of presentations that he invited representatives of the ICCCPPO board to the upcoming SIOF conference in Yokohama.

23 - 27 September 1997: Istanbul, Turkey

Members of the ICCCPPO-board got more and more involved in psychosocial issues and meetings of the PODC group of SIOF (Pediatric Oncology in Developing Countries). Together with physicians, psychologists and nurses, parents worked in committees developing official SIOF guidelines such as

- Guidelines for the communication of the diagnosis
- Guidelines for a Therapeutic Alliance between Families and Staff
- Guidelines for assistance to terminally ill children with cancer
- Valid Informed Consent and Participative Decision Making in Children with Cancer and their parents

... just to name a few (the texts can be found on the ICCCPPO website)





Rogelio Araujo Gil (Spain) joins the board



Sadie Cutland (South Africa, m.) with guests

2 - 6 September 1998: Frankfurt, Germany

It had been decided by the board and agreed upon by the general assembly that in cases where the SIOP conference would be held in places almost unattainable by the majority of the parent delegates (such as this time in Yokohama), another venue in a more central area should be chosen for the ICCCPPO general assembly.

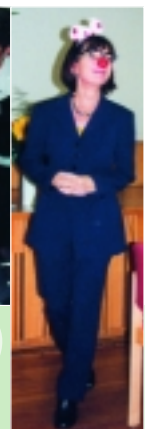
With its large international airport Frankfurt (Germany) seemed a good choice. The German group was able to extend a number of stipends for parents wanting to join from former East Block countries, and Lufthansa was very generous in supplying free flights for delegates coming from long distances such as New Zealand, Indonesia, South Africa, Kazakhstan or India.

All participants stayed in a boarding house that also provided the necessary conference rooms. This relatively sheltered atmosphere promoted almost automatically the information exchange among the delegates. And of course, a wine tasting evening with typical German food had to be part of the social program and enlightened the atmosphere.

Newly elected to the board were Rogelio Araujo Gil (Spain) and Simon Lala (New Zealand); and four new member organizations were admitted: Indonesia, Italy (National Federation), South Korea and Romania – as well as two associates from Australia and the UK.



Barbro Erikson (Sweden) Ex-secretary



1998



Handing over the ICCCP0 banner to the president of the Japanese group, Mr. Iwata

Organizing the meeting in Japan had put much strain on the ICCCP0 board. But an excellent meeting with plenty of delegates from Japan and other Asian countries such as South Korea and China made the effort worthwhile. On behalf of the Executive Committee, Sadie Cutland, Barbro Eriksson, Kurt Hansen, Marianne Naafs-Wilstra and Christine Wandzura, attended this meeting. They were assisted by: Annette Blomberg (Denmark), Hillary Cutland (South Africa), John Spinetta (USA) and Patricia Deasy-Spinetta (USA). The delegates were most generously hosted by CCAJ, the Japanese parent organisation, and Mr. Keiji Iwata, chairman of CCAJ.

7 - 8 October 1998 : Yokohama , Japan

Panel discussions on Long Term Survivors and Bereaved Families were attended by over 300 participants, parents and many professionals. About 175 people attended the session on School Issues. The workshops were very well attended by parents and volunteers of CCAJ and also the Camp session drew many people to the ICCCP0 room. For the Japanese parents simultaneous translation was available. Other interesting sessions were the psychosocial workshop, the PODC session and the Nurses' sessions. A visit to St. Luke's Hospital in Tokyo was scheduled where Dr. Hosoya showed us around.

The Vice-Chair, Marianne Naafs-Wilstra, spoke at the Opening ceremony of SIOP and was received in audience by the Crown Prince and Crown Princess of Japan, who were highly interested in the ICCCP0's work as well as in the work of CCAJ.





The “girls” of the board together with Eleanore Pask (Canada, sitting ri.), then responsible for the secretariat.

The survivors’ quilt handed over by Simone Mondelaers (Belgium)

11 - 14 September 1999: Montreal, Canada

In accordance with the Frankfurt meeting which managed to bring together many representatives from developing and former East Block countries, the board decided to grant travel stipends to those needing help. As ICCCPPO is still a legal body with only little revenues, many national groups contributed to the stipend funds and thus helped to enable the participation of many delegates.

The assembly elected Marianne Naafs-Wilstra (Holland) as Chairman, Mark Chesler (USA) as Vice-Chairman. Also on the board at that time were: Christine Wandzura (Canada), Simon Lala (New Zealand), Gerlind Bode (Germany), Sadie Cutland (South Africa), Regelio Araujo (Spain), David Orren (Israel) and Mokhtar El Harras (Morocco).

Nine organizations were admitted as full members: Bangladesh (ASHIC), Brazil, Bulgaria, Egypt, Israel, Lithuania, two from Russia, UK (NACCPO), and two associates from India and Luxembourg.



1999



Amsterdam - the city of the thousand channels - meant not only a boat tour but also that the delegates stayed in a boat-hotel and jointly took the streetcar to the exhibition hall, the venue of the SIOP conference. Many interesting lectures and engaged discussion and workshops were on the agenda.

5 - 7 October 2000: Amsterdam, the Netherlands

On the first evening of the meeting, all delegates joined in a "communal supper" as they had brought all kinds of typical food specialties from their home countries to try and share with others. Ever since then the idea of the "Meet and Greet" is part of the ICCCP program and helps to "break the ice" in the first hours of the meeting.

"Meet & Greet" with typical food from all delegates' countries

All member-organizations were given a copy of the book "You are not Alone" by Mark Chesler and Sara Eldrige. It is a valuable sourcebook for the "Support of Families of Children with Cancer" and is handed out to all new members as a special welcome gift.



Newly elected to the board was Geoff Thaxter (UK) as Gerlind Bode resigned after so many years of active involvement, yet is still responsible for the publication of the newsletter. She was granted honorary membership. The board made an issue to keep all those members who left the executive committee actively involved in committees supporting the growing workload of the board (such as the newsletter committee, the PODC-liaison and a group interested in social issues).

Eight new member organization were admitted: Australia (Tasmania), Bangladesh (CLASS), Colombia, Mexico, South Africa (national org.)

The board in 2000:
Mokhtar el Harras, Geoff Thaxter,
Rogelio Araujo, Simon Lala,
Marianne Naafs-Wilstra,
Sadie Cutland, Christine Wandzura,
Mark Chesler



2000

Four busy years



Marianne C.
Naafs-Wilstra
(Netherlands)
Chairperson
from
1999 to 2003

In the four years of my presidency we saw a tremendous growth in membership and programmes.

The Executive Committee laid much focus on developing countries. Limited treatment facilities, scarcity and the high price of medicines hamper continuous treatment of children in economically poor parts of the world and only 20% of the children with cancer in the world have access to optimum care.

ICCCPO officers were actively involved in the continental conferences in Africa, Asia and Latin America and we developed working relations with the SIOP Committee on Paediatric Oncology in Developing Countries (PODC). Both ICCCP and SIOP adopted the Early Warning Signs of Childhood Cancer developed by South African doctors and supported by CHOC (South Africa) to help people recognise symptoms and refer children to a specialised treatment centre.

We promoted Twinning between developed and developing countries and to enable representatives from less wealthy parts of the world to participate in our annual conference and AGA we established the so called Parents Helping Parents Fund (PHPF).

We drew up Guidelines for Standards of Treatment and Care which were adopted by SIOP and organised the first International Childhood Cancer Day (ICCD) in 2002. The ICCD is now a worldwide annual day to raise awareness and to raise funds.



A board meeting in Barcelona



We established an ICCCPO website, essential for benefits to be generated from it by our members or other interested viewers.

The ICCCPO world poster was developed and is being updated every year.

ICCCPO provided support to the survivors' network for their first meeting in 2001 and continued assistance in designing their programme and establishing their organisation.

We improved our internal operations. The Secretariat moved from Canada to the Netherlands, with some tasks taken up by Germany (printing and mailing of the Newsletter), New Zealand (financial report) and South Africa (website maintenance).

We developed a four year Business Plan and published quality printed annual reports.

Our financial position became more stable and we succeeded to raise funds for the ICCD, the Newsletter, the Annual Report, the PHPF and the survivors' conference. Besides we received some generous donations.

Though it was by times stressful, I consider it a great honour to have been president of ICCCPO over so many years. I was lucky to have some magnificent people working with me, both in the Executive Committee and in the other ICCCPO committees and to have the full support of all our members. When I handed over the chairperson's hammer to my successor Simon Lala, I knew he would lead us further to achieve our goals together ... because only together we can make a difference for the children and their families.



Parents and survivors meeting the cyclists from Germany

6 - 9 September 2001: Luxembourg, Luxembourg

As SIOP had decided to hold this year's annual meeting in Brisbane (Australia), ICCCPo convened again on more central European "turf". The Luxembourg organization "A heart for cancer sick children" had invited us all to a luxurious hotel setting with a full program of social events along with the formal meeting. It was also the first time that survivors attended the ICCCPo meeting (jointly and separately), topped by the arrival of the bicycle tour of young survivors from Germany who were greeted on the market place of the city of Luxembourg.

For the first time the board invited the assembly to an interactive board meeting which was designed to leave more time for thorough discussion of all topics of interest to the members. The interactive board meeting has become part of the AGA ever since.

The proposal to call for an International Childhood Cancer Day (by Geoff Thaxter, UK) was approved by the General Assembly and the 15th of January 2002 chosen to observe this event. Cancer Research UK, the supporting group of this day, prepared information material and brochures to be used by all participating groups.

After the contract with a company in Norway ended, Julian Cutland (South Africa) agreed to remodel, publish and host the ICCCPo Website under www.icccpo.org. This has become an enormously valuable information resource, always promptly updated and easily accessible. It lists all group addresses, presents all newsletters, the SIOP guidelines, the international bibliography, a search tool helps locate special articles according to their topics.

11 - 13 October 2001: Brisbane, Australian



The Australian setting provided the opportunity for a meeting of parents in South-East Asia/Australia (a large number of the participants came from New Zealand as this meeting was seen as a perfect opportunity for a regional meeting). The board members present were busily involved in an extensive program that dwelt on lectures on medical aspects, long term follow up, palliative care as well as organizational topics. The program had been organized and conducted jointly by Simon Lala from New Zealand and a representative from the host country in accordance to the local needs.



Tim Rogers, Royal Children's Hospital, Brisbane





15 – 19 September 2002: Porto, Portugal

Porto does not only mean having to taste the delicious Port Wine in one of the most prestigious Wine cellars – but it also meant a lot of work for the executive committee as many issues had to be taken care of, such as finding a new host for the secretariat as a change in the situation of the Canadian Candlelighters made the move necessary. The Dutch group offered to help and thus, all files and folders had to be shipped back to Europe again. Fortunately in the times of the internet, many documents are available as digital data, which makes a move like this a lot easier.

As the venue of the SIOP conference was a fair distance away from the hotel in which the parent meeting and the General Assembly took place, it had put a lot of organizational strain on the host parent group from Portugal, such as providing a bus-shuttle to carry delegates back and forth.

For the second time, survivors participated in the parents program and their own workshops. They got acknowledgement in a number of articles in the following ICCCPO newsletter. Ever since, all survivors interested are on the newsletter mailing list and are part of the information pool on the website.

The newly created "Parents Helping Parents Fund" received a great number of donations which allowed many representatives from less wealthy countries to participate in the meeting on travel stipends. Most of the survivors were supported either by their own country organizations or by the PHPF. This fund is one of the best examples of the sense of solidarity among all members.

With the election of Edith Grynszpancholic from Argentina and Ira Soelistyo from Indonesia, the new board represents almost all areas of the world: its delegates come from North and South America, from Africa, Europe and the South Pacific.

SIOP adopted the "Standards of Treatment and Care", a paper written by the ICCCPO-Board and proposed in 2001.



A survivors' panel

2002



Christine Wandzura, Secretary



In the midst of the still ongoing war in Iraq the board decided early in the year of 2003 to cancel ICCCP's participation in the SIOP conference in Cairo as no end of the war was in sight at that time. Too many obstacles could not be removed and were clearly a reason for cancellation. While staying at the campus of the Barretstown Gang Camp in Ireland for its mid-year meeting, the board made arrangements to host the fall meeting there.

It turned out to be a wise decision, though meanwhile the war had stopped and the dangers from any political impact upon the Cairo conference had become minimal.

3 - 5 October 2003: Barretstown, Ireland

The Barretstown staff had been enormously supportive in making this meeting possible and helped to ease where ever possible (such as providing a pick-up service from the airport). They even managed to encourage Irish parents to join in a national coalition. This new group was part of the meeting, which offered a very busy program with a broad selection of lectures and workshops on a variety of issues – and the fact that people could not "escape" from the grounds made them all become deeply involved. Camps for children with cancer (and their siblings) was one of the major topics, but also presentations by new parent groups from



2003



Armenia, Russia, Ukraine or as far remote as Hong Kong. Issues on fund raising and how to build and sustain a parent group in a developing country as opposed to a developed country were discussed in workshops and lectures.

The survivors – involved now for the third time – set up their own guidelines and governing body with a board responsible for contacts and exchange (speaker: Anthony Penn, UK). They organized their own program (main topic long term effects) and drafted a resolution on necessary long term support.

The AGA elected Simon Lala (New Zealand) for Chairman and Geoff Thaxter (UK) as Vice-Chair, thanking Marianne Naafs for her dedication as Chair of ICCCP0 over four years. The Dutch group (under the experienced supervision of Marianne Naafs) will continue to host the secretariat of ICCCP0 for an indefinite time. Newly elected to the board was Irina Ban from Serbia and Montenegro, replacing David Orren from Israel who could not join most of the meetings due to the political situation of his country.

The General Assembly admitted for membership groups from India, Hong Kong, South Korea, Paraguay, the Czech Republik, Bosnia Herzegovina and Russia.

**ICCCPO counts in 2004:
65 members
from 52 countries**



The present Executive Committee



Front left to right:

Irina Ban, Serbia and Montenegro

Marianne Naafs-Wilstra, The Netherlands

Ira Soelistyo, Indonesia

Middle left to right:

Christine Wandzura, Canada, (Secretary)

Simon Lala, New Zealand, (Chairman)

Edith Grynspancholc, Argentina

Back left to right:

Mark Chesler, USA

Julian Cutland, South Africa, (Treasurer)

Geoff Thaxter, United Kingdom, (Vice-Chairman)

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