

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

ANNUAL REPORT

2003



**International Confederation
of Childhood Cancer
Parent Organisations**

Annual Report of the Executive Committee, 2003

Annual Conference

The 2002 conference was held in Oporto, Portugal, from September 19 to 22. With the outstanding contribution of Acreditar, the Portuguese Parent Organisation, the organizing committee, chaired by Christine Wandzura of Canada, welcomed over 150 parents, survivors and professionals to four days filled with exceptional speakers, posters and networking opportunities. ICCCPPO was thrilled that so many of our participants were able to attend due to the support they received from ICCCPPO members through the Parents Helping Parents Fund. This conference continues to be one of the most important programmes we provide and was held in conjunction with the annual SIOP meeting so that we could organise several joint sessions. It also gave opportunities for interaction and networking.

Though the decision was not an easy one, the Executive Committee decided in March to move the 2003 annual conference from Cairo, Egypt, to Barretstown, Ireland due to the extremely unstable situation in the Middle East. The first idea was to still hold a regional parent meeting in Cairo but unfortunately, limited resources prevented us from organising two meetings within days of each other.

Regional meetings

ICCCPO held its first Asia Parent Meeting alongside the SIOP ASIA Conference in New Delhi (India). The parent programme focussed on the issues being faced by parent groups in developing countries. Four delegates of ICCCPPO (Simon Lala, Julian Cutland, Sadie Cutland and Gerlind Bode) were involved in designing the programme and chairing the meetings together with representatives of Sahayta from Chandigarh. The outcome was two very interesting days of intensive work, talks, reports, presentations, workgroups, round table discussions, as well as social events.

ICCCPO was involved in the SLAOP Conference in Managua, Nicaragua (the Latin American SIOP). Edith Grynszpancholc attended the parent meeting, presented a paper and met with a number of parent groups from Middle and South America.

The board is committed to holding future regional meetings provided our members in specific regions express enough interest.

International Childhood Cancer Day (ICCD)

The second International Childhood Cancer Day took place on 15th February, supported again by Cancer Research UK. 38 countries took part this year raising awareness of the 250,000 children who get cancer every year in the world. Another goal is to raise funds to support the work of member organisations. The official launch took place in London at the Cancer Research UK offices and was attended by Marianne Naafs-Wilstra (ICCCPO Chair) and Baroness Helene Hayman. Press conferences were held by member organisations throughout the world.

Members organised parties for children in hospitals and arranged special outings. Events were held to fundraise or to draw attention to the needs of the children. A compact disk containing full details of events in each country is available and is designed to share ideas between parent organisations all over the world. A copy has been sent to each member organisation.

Standards of Treatment and Care

This document sets out the basic standards families should expect through

the childhood cancer journey, and draws on the UN Charter on the Rights of the Child. It covers the journey from access to diagnosis and treatment, through to support in rehabilitation after treatment. The Standards set out what family expectations should be in relation to:

- Access to treatment
- Emotional support
- Social support
- Reintegration into society

The document has been drawn up with input from ICCCPPO and SIOP members, and was adopted by SIOP in Oporto 2002. The document can be found on our web site www.icccpo.org

Family Policy

Guidelines have been drafted and are under discussion. A comprehensive document is expected to be ready early next year.

Innovative Therapies for Children with Cancer (ITCC)

ICCCPO is full partner of the European consortium for Innovative Therapies for Children with Cancer. The aim of the ITCC is to enhance and facilitate access to potentially effective new anticancer therapies for children suffering from cancer and to conduct a paediatric therapeutic target identification research programme, in order to improve both the number of children cured and their quality of life. ICCCPPO has a role in improving information access and ethical aspects of clinical research.

Membership

The AGA in Oporto accepted two organisations as new members: The Parents Initiative from Ukraine as full member and Children's Cancer Club from Malawi as associate member. Membership discussions are in progress with some 20 organisations. The Executive Committee will recommend to the AGA in Ireland several new organisations.

Survivors network

ICCCPO provided support to the survivors' network for their meeting in Oporto and continued assistance in

Executive Committee 2002-3

- Marianne Naafs-Wilstra, chair (Netherlands)
- Simon Lala, vice-chair (New Zealand)
- Christine Wandzura, secretary (Canada)
- Julian Cutland, treasurer (South Africa)
- Mark Chesler (USA)
- Geoffrey Thaxter (UK)
- Ira Soelistyo (Indonesia)
- David Orren (Israel)
- Edith Grynszpancholc (Argentina)

The International Confederation of Childhood Cancer Parent Organizations

STATEMENT OF REVENUE, EXPENSES AND FUND BALANCE DECEMBER 31, 2002 > to be adopted

| | 2002 US\$ | 2001 US\$ |
|---------------------------------|---------------|---------------|
| Revenue: | | |
| Membership Fee | 13,397 | 13,245 |
| Interest and Sundry | 4 | 584 |
| Sponsorship | 26,463 | - |
| PHPF | 9,781 | - |
| Donations | 906 | - |
| Exchange Gains | 2,078 | - |
| Total Income | 52,629 | 13,829 |
| Expenses: | | |
| Executive Meetings | 2,840 | 3,804 |
| Office and General | 11 | 243 |
| Postage and Courier | 79 | 1,542 |
| Printing and Stationery | 505 | 1,476 |
| Professional Fees | 1,056 | 300 |
| AGA Scholarships | 18,559 | - |
| AGA Meeting Expenses | 2,813 | - |
| Regional Meetings | 3,552 | - |
| ICCD Expenses | 3,431 | - |
| Annual Report Expenses | 3,456 | - |
| Newsletter Costs | 3,138 | - |
| Bank Charges | 728 | - |
| Total Expenses | 40,168 | 7,365 |
| Excess of Income over Expenses | 12,461 | 6,464 |
| Fund Balance, beginning of year | 40,131 | 33,667 |
| Fund Balance, end of year | 52,592 | 40,131 |

designing their programme for 2003 and providing limited financial aid.

Developing countries and Twinning

Edith Grynszpancholic visited several Latin American groups, established contacts and provided a report on the present situation, the actual needs and the challenges for the future in that part of the world. From her report will come suggestions on how ICCCPPO can support these organisations more efficiently.

New contacts were made in Asia though the Asian meeting and networking by Ira Soelistyo. ICCCPPO encourages members to

participate in "twinning" programmes and a range of networking activities and we are witnessing more and more examples of mutual support.

Information and Communication

The newsletter is the forum of communication between parent organisations. It was published three times and distributed by mail and e-mail. It can also be downloaded from the ICCCPPO website. Volunteers form the editorial staff which is chaired by Gerlind Bode. The website is also a key source of information and Webmaster Julian Cutland was responsible for the maintenance and further expansion.

Public Relations and Awareness

The ICCD was again an excellent opportunity to draw attention to ICCCPPO and its goals and to raise awareness of childhood cancer throughout the world. The ICCCPPO world map was updated and illustrates the organisation's growth in membership and programmes. The annual report provides information about our activities and programmes – and for the third year the Lisa Thaxter Trust in the UK generously sponsored it.

Fundraising and Parents Helping Parents Fund

Our cornerstone development programme is the Parents Helping Parents Fund. It demonstrates the concerted effort to raise the funds needed to assist members from developing countries to attend our annual meetings. In 2002 nine members gave over 9,000 US\$ to help us achieve this goal. With the 10,000 US\$ that was provided for in the budget, we were able to grant 18 stipends to attend the Oporto meetings. This fund has now become an ongoing part of the ICCCPPO's annual appeal to members.

A process for increasing sponsorships for our vital programmes is under development. To that end we were thrilled to receive a generous sponsorship for the 2003 Barretstown Conference from CLIK-UK.

The Executive Committee worked further on the creation of the Case Statement - the basis of our fundraising operations. The Case Statement articulates the needs, goals and the necessary funds to carry out our work.

Internal operations

In March the Executive Committee met in Ireland at the Barretstown Gang Camp at the same time a meeting with a national Irish parent group-to-be was scheduled.

As ICCCPPO membership has increased, there is a corresponding need to regionalize committees. The Executive Committee has been working on the development of regional structures to provide relevant support and increased representation at a continental level. It will likely take a year or more until this new structure can commence.

The International Confederation of Childhood Cancer Parent Organisations (2002/3)

| ORGANIZATION | COUNTRY | EMAIL |
|---|----------------|---|
| Fundación Natalí Dafne Flexer | ARGENTINA | funflex@sinectis.com.ar |
| Cancer Council of Tasmania | AUSTRALIA | megan@cancertas.org.au |
| Children's Leukaemia and Cancer Society Inc | AUSTRALIA | ceo@clcs.org.au |
| Kinder - Krebs - Hilfe (Dachverband) | AUSTRIA | dachverband@kinderkrebshilfe.at |
| ASHIC (A Shelter for Helpless Ill Children) Foundation for Childhood Cancer | BANGLADESH | ashic@citechco.net |
| Children Leukaemia Assistance & Support Services (CLASS) | BANGLADESH | class@globalctg.net |
| Núcleo de Apoio à Criança com Câncer - NACC | BRAZIL | nacc@elogica.com.br |
| The "Tashko" Humanitarian Foundation | BULGARIA | tashko@plov.omega.bg |
| Candlelighters Childhood Cancer Foundation Canada | CANADA | staff@candlelighters.ca |
| Kids Cancer Care Foundation of Alberta | CANADA | wandzura@kidscancercare.ab.ca |
| Colombian Childhood Cancer Parents Organization & Relationship Diseases (OPNICER) | COLOMBIA | jabisambra@lasc.com.co / opincer@opincer.org |
| Sanus | CROATIA | srđjana.culic@st.tel.hr |
| Grupo de Apoyo de Padres de Niños Oncológicos "El Principito" | CUBA | calderon@infomed.sld.cu |
| Forældreforeningen Barn og Unge med Kræft | DENMARK | ff@foraeldreforeningen.dk |
| Alexandria Group of Childhood Cancer Care (AGCCC) | EGYPT | ysaad_eldin@yahoo.com |
| SYLVA | FINLAND | syopa.lapset@sylva.inet.fi |
| L'ENVOL | FRANCE | lenvol@aol.com |
| DLFH (Deutsche Leukämie-Forschungshilfe) | GERMANY | dlfhbonn@t-online.de |
| Floga - Parents' Ass. of Children with Cancer | GREECE | f2001@otenet.gr |
| IASO | GREECE | 30-41-550-060 |
| Styrktarfélag Krabbameinssjúkra Barna | ICELAND | skb@skb.is |
| Sahayta Charitable Welfare Society | INDIA | sahayta@satyam.net.in |
| Indonesian Childhood Cancer Foundation (Yayasan Onkologi Anak Indonesia) | INDONESIA | yoai2008@indosat.net.id |
| Society To Support Children Suffering From Cancer known as 'MAHAK' | IRAN | info@mahak-charity.org |
| The Barretstown Gang Camp | IRELAND | ciara.casey@barretstowngc.ie |
| CHAYIM - For Children With Cancer In Israel | ISRAEL | hayim83@zahav.net.il |
| Comitato Maria Letizia Verga | ITALY | cmlv@brianzaonline.it / pia.bonini@tiscalinet.it |
| Federazione Italiana delle Associazioni di Genitori di Oncoematologia Pediatrica | ITALY | fiagop@tin.it |
| Children's Cancer Association of Japan | JAPAN | nozomi@ccaj-found.or.jp |
| Latulan Childhood Cancer Society | LATVIA | |
| Lithuanian Society of Children With Onkohematological Diseases "Paguoda" | LITHUANIA | paguoda@post.com |
| Een Haerz fir kriibskrank Kanner a.s.b.l. | LUXEMBURG | icccpo@kriibskrankanner.lu |
| Children's Cancer Club | MALAWI | emolyneux@malawi.net |
| AMANC, Asociación Mexicana de Ayuda a Niños con Cancer, I.A.P. | MEXICO | amanc1@terra.com.mx |
| L'Avenir | MOROCCO | mokhtar@iam.net.ma |
| Vereniging 'Ouders, Kinderen en Kanker' (VOKK) | NETHERLANDS | mc.naafs@vokknl / bureau@vokk.nl |
| Child Cancer Foundation | NEW ZEALAND | info@childcancer.org.nz |
| Asociación de Padres de Niños Con Leucemia y Cancer | NICARAGUA | drcardenas@yahoo.com |
| Stotteforeningen for Kerfetsyke Barn (SKB) | NORWAY | skb@kreft.no |
| Associação Acreditar | PORTUGAL | acreditar@mail.telepac.pt |
| P.A.V.E.L. | ROMANIA | pavel_romania@hotmail.com / olga_rodicah@hotmail.com |
| Novosibirsk City Foundation for Aid to Invalid Children | RUSSIA | proskuryakova@mail.ru |
| Children and Parents Against Cancer | RUSSIA | childrencancer@peterlink.ru / sukhovskaia@mail.ru |
| Parents Against Cancer Plus | RUSSIA | kondrasheva@mail.ru |
| CHOC Childhood Cancer Foundation South Africa | SOUTH AFRICA | national@choc.org.za |
| Federación Española de Padres del Niños con Cáncer | SPAIN | federacion@cancerinfantil.org |
| Barncancerfonden | SWEDEN | info@barncancerfonden.se |
| Kinderkrebshilfe Schweiz | SWITZERLAND | info@kinderkrebshilfe.ch |
| Mercy Mission 'Overcoming' | UKRAINE | hemato@simfi.net |
| National Alliance of Childhood Cancer Parent Organizations (NACCP0) | UNITED KINGDOM | thaxter@litrust.freemove.co.uk |
| United Kingdom Children's Cancer Study Group (UKCCSG) | UNITED KINGDOM | ukccsg@le.ac.uk |
| Cancer & Leukaemia in Children (CLIC) | UNITED KINGDOM | clic@clic-charity.demon.co.uk |
| Candlelighters Childhood Cancer Foundation | USA | info@candlelighters.org |
| Asociación Venezolana de Padres de Niños con Cancer Servicio de Oncología | VENEZUELA | rosybriceno@cantv.net |
| Uvek sa Decom /Ass. Always with Children | YUGOSLAVIA | jelenabo@eunet.yu / rtimotic@Eunet.yu |
| Zvonica | YUGOSLAVIA | ban@yubc.net |