

Members

| | | | |
|--|------------------------|--|---|
| Fundación Natalí Dafne Flexer | ARGENTINA | edith@fundacionflexer.org | www.fundacionflexer.org |
| Society to Help Children with Cancer | ARMENIA | badalyan@doctor.com | |
| Cancer Council of Tasmania | AUSTRALIA | megan@cantatas.org.au | www.cantatas.org.au |
| Children's Leukaemia and Cancer Society Inc. | AUSTRALIA | ceo@clcs.org.au | www.clcs.org.au |
| Kinder - Krebs - Hilfe (Dachverband) | AUSTRIA | dachverband@kinderkrebshilfe.at | www.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 | |
| Heart for Kids with Cancer | BOSNIA AND HERZEGOVINA | srcefbih@yahoo.com | www.screzadjecu.freewebspace.com/index.html |
| 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 | www.candlelighters.ca |
| Kids Cancer Care Foundation of Alberta | CANADA | wandzura@kidscancercare.ab.ca | www.kidscancercare.ab.ca |
| Little Life Warrior | CHINA | childcancure@cuhk.edu.hk | www.childcancure.org.hk |
| Columbian Childhood Cancer Parents Organization & Relationship Diseases OPNICER | COLUMBIA | opnicer@opnicer.org | www.opnicer.org |
| Sanus | CROATIA | sanus@st.hinet.hr | www.sanus.hr |
| Grupo de Apoyo de Padres de Ninos Oncologicos "El Principito" | CUBA | calderon@infomed.sld.cu | |
| Sdru_í_ance | Czech Republic | edvorakova@tiscali.cz | www.sancecz.org |
| Forældreforeningen Barn og Unge me 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 | www.l-envol.org |
| DLFH (Deutsche Leukämie-Forschungshilfe) | GERMANY | dlfhbonn@t-online.de | www.kinderkrebsstiftung.de |
| Floga - Parents' Ass. of Children with Cancer | GREECE | f2001@otenet.gr | |
| IASO | GREECE | non listed | |
| Styrktarfelag Krabbameinssjúkra Barna | ICELAND | skb@skb.is | |
| Sahayta Charitable Welfare Society | INDIA | sahayta@satyam.net.in | |
| Indonesian Childhood Cancer Foundation (Yayasan Onkologi Anak Indonesia) www.onkologianak.org / childhoodcancer.id.org | INDONESIA | yoai2008@indosat.net.id | |
| Society To Support Children Suffering From Cancer Known as "MAHAK" mahak-charity.org | IRAN | info@mahak-charity.org | www.mahak-charity.org |
| The Barretstown Gang Camp | IRELAND | ciara.casey@barretstowngc.ie | |
| CHAYIM - For Children With Cancer In Israel | ISRAEL | hayim@actcom.net.il | |
| Comitato Maria Letizia Verga | ITALY | comitato.verga@pediatriamonza.it | |
| Federazione Italiana delle Associazioni di Genitori di Oncoematologia Pediatrica fiagop.it | ITALY | info@fiagop.nl | www.filagop.nl |
| Children's Cancer Association of Japan | JAPAN | nozomi@ccaj-found.or.jp | www.ccaj-found.or.jp |
| Korean Association for Children with Leukemia and Cancer Korea | KOREA | miokcho@unitel.co.kr | www.soaam.or.kr |
| Latvian 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 | www.kriibskrankanner.lu |
| Children's Cancer Club | MALAWI | emolyneux@malawi.net | |
| AMANC, Asociacion Mexicana de Ayuda a Ninos con Cancer, I.A.P. | MEXICO | amanc1@amanc.org | |
| L'Avenir | MOROCCO | avenir.2@iam.net.ma | www.almoustakbal.org |
| Vereniging 'Ouders, Kinderen en Kanker' (VOKK) | NETHERLANDS | mc.naafs@vokk.nl / bureau@vokk.nl | www.vokk.nl |
| Child Cancer Foundation | NEW ZEALAND | info@childcancer.org.nz | www.childcancer.org.nz |
| Asociacion de Padres de Ninos Con Leucemia y Cancer | NICARAGUA | drcardenas@yahoo.com | |
| Stotteforeningen for Kreftsyke Barn (SKB) | NORWAY | skb@kreft.no | www.kreftsyke-barn.no |
| MITA'I Asociacoón de de Padres para ayuda a niños con cancer | PARAGUAY | mitai@conexion.com.py | |
| Associacao Acreditar | PORTUGAL | acreditat@mail.telepac.pt | |
| P.A.V.E.L. | ROMANIA | pavel_romania@hotmail.com / olga_rodicah@hotmail.com | www.pavelromania.ro |
| asociatiapavel.home.ro | | | |
| "Novosibirsk City Foundation for Aid to Invalid Children With Oncohematologic Diseases" | RUSSIA | proskuryakova@mail.ru | |
| CAPAC, Children and Parents Against Cancer | RUSSIA | childrencancer@peterlink.ru | www.deti.blood.ru |
| Parents Against Cancer Plus | RUSSIA | kondrasheva@mail.ru | |
| Triendinstvo | Russia | ninacost@atnet.ru | |
| ISKORKA | Russia | ohc@mail.ru; vera1@fromru.com | |
| Regional Charity Organization for helping Children in behalf of St. Elizabeth | Russia | | tony_m02@mail.ru / |
| elisabethorg@list.ru | | | |
| Uvek sa Decom /Ass. Always with Children | SERBIA AND MONTENEGRO | sadecom@eunet.yu | |
| Zvoncica | SERBIA AND MONTENEGRO | ban@yubc.net | |
| CHOC National | SOUTH AFRICA | national@choc.org.za | www.choc.org.za |
| Federación Española de Padres del Niño con Cáncer | SPAIN | federacion@seppninfantil.org | www.seppninfantil.org |

Statement of revenue, expenses and fund balance December 31, 2003 > to be adopted

| | 2003 US\$ | 2002 US\$ |
|---------------------------------|---------------|---------------|
| Revenue: | | |
| Membership Fees | 16,693 | 13,397 |
| Interest | 1,315 | 4 |
| Sponsorship | 31,137 | 26,463 |
| PHPF | 11,419 | 9,781 |
| Donations | 1,115 | 906 |
| Exchange Gains | 9,694 | 2,078 |
| Total Income | 71,373 | 52,629 |
| Expenses: | | |
| Executive Meetings | 5,320 | 2,840 |
| Office and General | - | 11 |
| Postage and Courier | - | 79 |
| Printing and Stationery | 200 | 505 |
| Professional Fees | 500 | 1,056 |
| AGA Scholarships | 8,641 | 18,559 |
| AGA Meeting Expenses | - | 2,813 |
| Regional Meetings | 983 | 3,552 |
| ICCD Expenses | 7,964 | 3,431 |
| Annual Report Expenses | 2,901 | 3,456 |
| Newsletter Costs | 4,042 | 3,138 |
| Bank Charges | 711 | 728 |
| Total Expenses | 31,262 | 40,168 |
| Excess of Income over Expenses | 40,111 | 12,461 |
| Fund Balance, beginning of year | 52,592 | 40,131 |
| Fund Balance, end of year | 92,703 | 52,592 |



Executive Committee 2003/4

Simon Lala, Chair *(New Zealand)*
 Geoff Thaxter, Vice-Chair *(UK)*
 Christine Wandzura, Secretary *(Canada)*
 Julian Cutland, Treasurer *(South Africa)*
 Marianne Naafs-Wilstra *(The Netherlands)*
 Mark Chesler *(USA)*
 Ira Soelistyo *(Indonesia)*
 Edith Grynspanchoc *(Argentina)*
 Irina Ban *(Serbia & Montenegro)*

ANNUAL REPORT
2004

On behalf of the Executive Committee, I am pleased to report on the continued growth of the ICCCPPO and its achievements over the past year.

Annual Conference

The 2003 Conference was held in Barretstown, Ireland and was beneficial for all members that attended. Although the meeting was not held in conjunction with SIOP, we were still able to secure excellent speakers to present lectures on medical and psychosocial issues affecting childhood cancer.

This meeting was unique in that it was held at The Barretstown Gang Camp situated in the Irish countryside where delegates were able to experience real camp life and the hospitality of the local community.

The venue choice was made at a relatively short notice for such a conference and we must acknowledge the contribution and logistical support by the Barretstown staff and the ICCCPPO organising committee.

10th Anniversary

May 2004 marked the tenth anniversary of ICCCPPO. An International meeting held in Valencia where ICCCPPO was incorporated commemorated the occasion. The meeting was hosted by Aspanion on behalf of the Spanish Federation. The Executive Committee took the opportunity to hold its mid year meeting in Valencia to be able to take part in the conference & celebrations. We thank Jesus Gonzales, Aspanion and the Spanish Federation for their generous hospitality and event organisation. Further celebration of the Anniversary is planned for Oslo.

Survivors Network

ICCCPPO continues to work with an international group of survivors. Their long-term goal is to create an International Childhood Cancer Survivor Network. To this end, each year for the past four years, we have enjoyed the participation of national survivor group's participants who meet at the same time as our annual international meetings.

In 2003 twenty-one survivors, ranging from sixteen to twenty-nine years of age, met in Barretstown, Ireland. Their meeting included technical lectures of medical and psychosocial aspects of survivorship, a work session focusing on how to establish and sustain survivor groups in different nations, a session on supportive and recreational therapy, and a series of interactive sessions where participants shared their personal experiences and wisdom with one another. Social events were also held.

Plans are underway with representatives of this group to plan their sessions in Oslo. In addition, the ICCCPPO Survivor's Group has developed a mission statement and goals, and has elected an executive chaired by Anthony Penn.

Plans for cross representation at the Executive Committee level are being developed.

Membership

ICCCPPO continues to grow in membership. We have developed contacts with a large number of parent organisations, especially in the less affluent nations of the world.

The AGA in Barretstown approved six new organisations as full members, namely: Bosnia Herzegovina, Czech Republic, Hong Kong, Paraguay, Russia, South Korea and Sahayta from India (previously an associate). Armenia was approved as a new associate member.

International Childhood Cancer Day (ICCD)

This year's International Childhood Cancer Day saw ICCCPPO appeal to United Nations Secretary General, Kofi Annan to obtain equality in treatment for children with cancer around the world. Under the UN Charter on the Rights of the Child, every child has the right to life, treatment when ill and rehabilitation.

A UN agency has responded to the appeal and ICCCPPO, along with SIOP, are now in dialogue with them to see how the parties can work together in the transfer of knowledge and skills from one country to another. The appeal has also received support from a number of governments around the world.

Cancer Research UK has played a key role in raising the profile of this appeal in the media. TV and media coverage has helped to draw the appeal to the attention of agencies like the UN.

The ICCD was celebrated in over thirty countries throughout the world. There were organised parties for the children in hospitals, conferences, media coverage and fundraising events in support of childhood cancer charities, both local and worldwide. A CD covering member's events will be available at the Annual Conference and distributed to those who do not attend.

Family Policy

The Executive Committee is currently reviewing a comprehensive paper on this subject and this will be presented for adoption at the AGA in Oslo.

Innovative Therapies for Children with Cancer (ITCC)

ICCPO is a full partner of the European Consortium for Innovative Therapies for Children with Cancer (ITCC). The aim of ITCC is to enhance and facilitate access to potentially effective new anti-cancer therapies for children suffering from cancer and to conduct a paediatric therapeutic target identification research program, in order to improve both the number of children cured and their quality of life. ICCCPPO plays a significant role in improving information access and ethical aspects of clinical research in children with life-threatening diseases.

Cochrane Childhood Cancer Review Group (CCCRG)

The Cochrane Childhood Cancer Review Group will stimulate well-informed decisions about healthcare in children with cancer. Activities of the CCCRG will be to coordinate the preparation, production, and maintenance of systematic reviews on the effect of interventions in children with cancer and to maintain a trial register of existing clinical trials in children with cancer. ICCCPPO represents the "consumers", an important partner in any Cochrane Review group.

Information and Communications

Three issues of the ICCCPPO-Newsletter were published in 2003 and were received by about 250 addresses worldwide – parent groups, doctors and the interested public. The newsletter remains a vital information tool with many interesting and stimulating contributions in the field of cancer in childhood all over the world. The distribution has become even faster by sending it as a digital version to those who provided us with their email addresses. As the newsletter is always promptly available on the website we can assume that an even larger number of readers will be reached. We would like to urge all groups and individuals to send us their contributions to maintain the diversity of this publication.

The ICCCPPO website has now been fully developed and provides a good profile of our organisation and is another key source of information on childhood cancer. The number of "hits" that our website receives is very encouraging; it has grown from an average of 33 per day in 2002, to 95 in 2003, and to about 120 per day in 2004. This equates to some 24,000 visitors to the site in the first seven months of 2004.

The bibliography that contains members' publications is currently under revision. The new focus will be how to obtain a copy of these publications, reprint and content details. Since this information changes so often, the bibliography will continue to be located only on our website.

Fundraising and Parents Helping Parents Fund

Our primary source of fundraising is through our membership fees and direct sponsorship of programs. We are very grateful for these generous gifts from our benefactors. The Parents Helping Parents Fund demonstrates our members' desire to look after parents from developing countries. It is through these gifts that 11 members were able to provide gifts totalling \$11,419, so that our peers could attend the annual conferences.

The Executive Committee continues to define and prioritise programs that would benefit members in the most significant way. To that end, the focus is to seek financial support for these programs from agencies, corporations and individuals that wish to make an impact into childhood cancer programs throughout the world.

Internal Operations

The ICCCPPO secretariat has continued to be kindly hosted by the Netherlands Parent Organisation – Vereniging Ouders, Kinderen en Kanker (VOKK).

Regional Meetings

The Executive Committee has been working on the establishment of regional meetings. The objective of such meetings is to provide a forum for delegates to share local concerns and develop strategies that might better serve their region, with possible assistance from fellow ICCCPPO members. A first meeting was held in St Petersburg, Russia, with a number of Russian and Ukrainian groups attending.

Finances

The fund balance in 2003 was strong and represents approximately 18 months of expenditure held in reserves. However the Executive Committee remains cautious in its planning until it is able to secure longer term sponsorship agreements.

Volunteers

The work of the ICCCPPO is done on a voluntary basis and I would like to take this opportunity to thank the Executive Committee and those who serve on various sub committees.

We are all driven by a strong desire to make a difference in the lives of children with cancer and their families. It is the children and their families who inspire the work we do – it is their strength and determination that encourages us to put forth our best efforts and build a strong and sustainable organization. In the coming years, we will continue to look for new ways to diminish the impact this terrible disease has on children and their families