



THE INTERNATIONAL
CONFEDERATION OF
CHILDHOOD
CANCER PARENT
ORGANIZATIONS

2005
Annual
Report

Fundación Natalí Dafne Flexer Society to Help Children with Cancer Cancer Council of Tasmania Children's Leukaemia and Cancer Society Inc. Kinder - Krebs - Hilfe (Dachverband)	ARGENTINA ARMENIA AUSTRALIA AUSTRALIA AUSTRIA BANGLADESH BANGLADESH BOLIVIA BOSNIA AND HERZEGOVINA	edith@fundacionflexer.org badalyan@doctor.com megan@cancertas.org.au ceo@clcs.org.au dachverband@kinderkrebshilfe.at ashic@citechco.net class@globalctg.net yolandaernst@hotmail.com srcefbih@yahoo.com	www.fundacionflexer.org www.cancertas.org.au www.clcs.org.au www.kinderkrebshilfe.at www.afanic.com www.screzadjecu. freewebspace.com/index.html
ASHIC CLASS AFANIC Heart for Kids with Cancer	BRAZIL BULGARIA CANADA CANADA CANADA CHINA CHINA COLUMBIA CROATIA CUBA	nacc@elogica.com.br tashko@plov.omega.bg dstones@candlelighters.ca dmornar@cw.bc.ca wandzura@kidscancercare.ab.ca childcancure@cuhk.edu.hk info@pkwfoundation.org opnicer@opnicer.org sanus@st.hinet.hr calderon@infomed.sld.cu	 www.candlelighters.ca www.kidscancer.bc.ca www.kidscancercare.ab.ca www.childcancure.org.hk www.opnicer.org www.sanus.hr
NACC The "Tashko" Humanitarian Foundation Childhood Cancer Foundation Candlelighters Canada BC Childhood Cancer Parents' Association Kids Cancer Care Foundation of Alberta Little Life Warrior Society Pau Kwong Wun Charitable Foundation OPNICER Sanus Grupo de Apoyo de Padres de Ninos Oncologicos "El Principito" Sdružení Šance Familier med kraeframte boern (FMKB) ASONIC Alexandria Group of Childhood Cancer Care (AGCCC) ASAPAC SYLVA UNAPECLE L'ENVOL DLFH Floga IASO Styrktarfelag Krabbameinssjúkra Barna Sahayta Charitable Welfare Society Cankids....kidscan	CZECH REPUBLIC DENMARK ECUADOR EGYPT EL SALVADOR FINLAND FRANCE FRANCE GERMANY GREECE GREECE ICELAND INDIA INDIA	edvorakova@tiscali.cz info@fmkb.dk asonic-ec@zona-andina.net ysaad_eldin@yahoo.com ceciliamoreno@telesal.net syopa.lapset@sylva.inet.fi unionparents@aol.com lenvol@aol.com dlfhbonn@t-online.de f2001@otenet.gr non listed skb@skb.is sahayta@satyam.net.in icansoc@nda.vsnl.net.in poonambagai@rediffmail.com yoai2008@indosat.net.id	www.sancecz.org www.fmkb.dk www.l-envol.org www.kinderkrebsstiftung.de www.skb.is www.cankidsindiaa.com
Indonesian Childhood Cancer Foundation (Yayasan Onkologi Anak Indonesia) Society To Support Children Suffering From Cancer Known as "MAHAK" TCCUP The Barretstown Gang Camp CHAYIM - For Children With Cancer In Israel Comitato Maria Letizia Verga	INDONESIA IRAN IRELAND IRELAND ISRAEL ITALY	info@mahak-charity.org michelle@tccup.com ciara.casey@barretstowngc.ie hayim@actcom.net.il comitato.verga@pediatrionza.it	www.onkologianak.org childhoodcancer.id.org www.mahak-charity.org www.tccup.com

Federazione Italiana delle Associazioni di Genitori di Oncoematologia Pediatrica
Children's Cancer Association of Japan
Korean Association for Children with Leukemia and Cancer
Latulan Childhood Cancer Society
Paguoda
Een Häerz fir kriibskrank Kanner a.s.b.l.
Children's Cancer Club
AMANC
con Cancer, I.A.P.
L'Avenir
Vereniging 'Ouders, Kinderen en Kanker' (VOKK)

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www.cancerinfantil.org

www.barncancerfonden.se

www.kinderkrebshilfe.ch

www.losev.org.tr

hematolog.vinchi.ru

hematolog.simfi.net

SPAIN

SWEDEN

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UKRAINE

UNITED KINGDOM

UNITED KINGDOM

UNITED KINGDOM

UNITED KINGDOM

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Child Cancer Foundation
Asociacion de Padres de Ninos Con Leucemia y Cancer
Stotteforeningen for Kreftsyke Barn (SKB)
MITA'I Asociacoón de de Padres para ayuda a niños con cancer
Acreditar
P.A.V.E.L.

Novosibirsk City Foundation for Aid to Invalid Children With Oncohematologic Diseases
CAPAC
Triendinstvo
ISKORKA

Regional Charity Organization for helping Children in behalf of St. Elizabeth
Uvek sa Decom
Zvonica
CHOC National
Federación Española de Padres del Niños con Cáncer
Barncancerfonden
Kinderkrebshilfe Schweiz
LÖSEV
Mercy Mission "Overcoming"

Charitable Fund VIDEN
NACCPPO
UKCCSG
CLIC
Sargent Cancer Care for Children
Candlelighters Childhood Cancer Foundation
Asociacion Venezolana de Padres de Ninos con Cancer Servicio de Oncologia

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 Grynszpancholc (Argentina) • Irina Ban (Serbia & Montenegro)

2004/5
Executive Committee



Inspired by ICCCPPO we formed a parent group, which has encouraged parents to share their pain and to receive hope, and provide a healing touch. Our volunteers have become more professional and compassionate.

Neelu Tuli, Sahayta India

We benefit from the exchange with the other countries, their ideas and programs, and how they are dealing with difficulties. We are grateful for the excellent networking and to know we are not alone.

Marianne Würsch, Kinderkrebshilfe Switzerland

Our view on childhood cancer has been broadened to the global level. ICCCPPO has also enhanced our awareness on the percentage of children who are receiving treatment. It will assist us in enhancing awareness in other provinces of China to treat cancer children in an earlier stage.

Brenda Chan, The Little Life Warrior Society Hong Kong China

Joining ICCCPPO has made a great contribution to our organization, for example, from the work of other organizations we have created different volunteer groups - parents; cancer survivors; psychologists; students.

Katerina Kisseleva, Children and parents against cancer St-Petersburg Russia

ICCCPPO is the best platform for members to forge co-operation, understanding and exchange of views around the world and thus expand activities and support beyond local boundaries.

Salma Choudhury, ASHIC Bangladesh

ICCCPPO played a large role in the development of a UK-wide parent organisation and helped develop our relationships within the EC and worldwide.

Geoff Thaxter, NACCPO United Kingdom

ICCCPPO inspires us. Some of our programs are based upon programs from other members and some of our programs are adopted by other members. Sharing and not inventing the wheel all over again. Solidarity!

Marianne Naafs, Vereniging Ouders, Kinderen en Kanker Netherlands

The greatest ICCCPPO idea has been to declare an International Day of Childhood Cancer. It provides the opportunity for our association to raise awareness for an early diagnosis and high curability of this disease with proper treatment.

Fouzia Msefer Alaoui and Mokhtar el Harras, l'Avénir Association Morocco

To get cancer at an early age makes one a special person - we have trained young survivors to help those children diagnosed with cancer in Finland. Through the ICCCPPO, we have understood the importance of getting together and influencing the conditions of cancer children at an international level.

Tuula Virkunen, Sylva, Finland

As usual, I came back to the Ukraine from the ICCCPPO conference very inspired and with a lot of ideas. It's like a sip of fresh air to be among strong people. It is really a great honour and responsibility for Viden to be a member of ICCCPPO.

Svetlana Shut, Viden, Ukraine

The ICCCPPO provides us with a chance to learn, share and give back. It motivates us to learn about the needs of others and to do whatever we can to change the outcomes for so many children ... now and in the future.

Christine Wandzura, Kids Cancer Care Foundation of Alberta, Canada

In 2004-2005, the International Confederation of Childhood Cancer Parent Organizations (ICCPO) continued to focus on its mission: “To share information and experience in order to improve access to the best possible care for children with cancer everywhere in the world”. We have been able to accomplish this with the combined efforts of a dedicated board, many volunteers and our members who benefit from and, in turn, help the Confederation with its programs and services.

On behalf of the Executive Committee, the following report outlines the activities and progress of ICCCPPO over the past year.

Annual Conference

The 2004 Conference was held in Oslo, Norway in conjunction with the International Society of Paediatric Oncology (SIOP). There were over 100 parents and survivors in attendance to take part in the informative sessions and networking opportunities. The annual conference continues to be the primary method by which we connect parents' groups. Survivors' groups are also benefiting from the sharing of best practices, program ideas, fundraising, marketing and public relations. Our sincerest thanks to Støtteforeningen for Kreftsyke Barn (SKB) and their team of volunteers and staff for being such gracious hosts. Thanks also to Marianne Naafs who crafted the conference program and arranged for the speakers and chairs.

The next conference will be held in Vancouver, Canada in September 2005.

Membership

At the last AGA held in Oslo, seven organizations were accepted for full membership and five organizations for associate membership. This brings the ICCCPPO membership to 76 member organizations from 57 countries. As part of their duties, the Board members try to visit members wherever possible to show their support and provide encouragement. For example, recent visits to Belgrade, Singapore, Hong Kong and Brazil were no exception and there are indications of wonderful support and programs being offered by the parent groups in these countries.

International Childhood Cancer Day – February 15th

This year's International Childhood Cancer Day was marked with the “Through My Eyes: A Day in the Life of Children with Cancer Around the World” project, encouraging children in the hospital to take pictures on the day to show how they saw life.

Thirty member countries ran events in their own countries. These ranged from raising awareness and raising funds to having events and parties for children. The Executive Committee has been in early discussions with the International Union Against Cancer (UICC) about how we might coordinate World Cancer Day on the 4th of February and the International Childhood Cancer Day on the 15th of February. Proposals will be brought to the members at the AGA in Vancouver.

Survivors Network

The survivors group has now become an established part of the ICCCPPO family. Since its formation, more and more survivors' groups have shown their support by attending the annual conferences where lectures and workshops addressing their particular needs have been organised. The survivors now have their own executive committee, which reports to the ICCCPPO Board and they have completed their own mission statement and goals. The generous sponsorship of CLIC is acknowledged for its part in the success of the survivor's network.

On behalf of the Board, Mark Chesler has played a pivotal role in the liaison between the parents and the survivors. Mark has successfully managed to secure a grant from the Lance Armstrong Foundation to support the expansion of the survivors meeting in Vancouver.

Collaboration

The Board has continued to develop its working relationship with the SIOP Board at both the international and regional levels. We have enjoyed the benefits of sharing ideas and resources during the joint sessions of our respective board meetings. Of special note is the collaboration on the new photo project, “Through My Eyes”, which will be launched this year at the SIOP/ICCPO meetings in Vancouver, Canada.

ICCPO has endorsed the SIOP mission statement trying to persuade the World Health Organization (WHO) to put children's cancer drugs on the essential drug list. Working together, ICCCPPO and SIOP are powerful allies in the fight against childhood cancer.

ICCPO is full a partner of the European Consortium for Innovative Therapies for Children with Cancer (ITTC) in order to develop a joint strategy for optimal information for patients and parents in terms of availability of clinical trials. ICCCPPO will contribute to ITCC in terms of medical-ethical aspects of inclusion of children with cancer in early clinical trials.

In October Marianne Naafs attended a lunch debate of the European Union (EU) with members of the European Parliament in Strasbourg, France, where ICCCPPO and SIOP Europe emphasized the need to improve the outlook for children with cancer all across Europe.

In the first half of 2005 ICCCPPO was involved in a European campaign to gain votes in favour of the newly proposed European Regulation for Paediatric Drugs.

ICCPO works closely with the Cochrane Childhood Cancer Review Group (CCCRG) and represents the consumers, an important partner in any reviews by the CCCRG. The function of the CCCRG is to co-ordinate the preparation, production and maintenance of systematic reviews on the effects of interventions in children with cancer and to maintain a trial register of existing clinical trials in children with cancer.

Information and Communications

Starting with the year 2004, the number of newsletter issues was limited to two per year – each filled with many interesting contributions by parents, survivors, medical and psychosocial staff. Published are presentations held at meetings, reports about ICCCPPO's current activities, personal experiences by parents and survivors as well as book reviews. The ICCCPPO newsletter is shipped to member organizations as well as to interested individuals via postal and electronic mail. It can also be obtained easily in PDF format from the website. ICCCPPO's tenth anniversary in 2004 was commemorated in a special booklet, which can be ordered from the secretariat.

The ICCCPPO website (www.icccppo.org) is continually being updated to provide excellent information on childhood cancer. The number of visitors to the site has grown steadily and now averages over 50,000 per year.

Regional Meetings

The Board strongly supports the concept of holding more regional meetings with the goal of reaching out to more parents in a particular region where closer networking and sharing of experiences is desired.

Over the past year, very successful regional meetings were held in Belgrade, Serbia and Montenegro and Campo Grande, Brazil with positive feedback from the many surrounding countries that attended. Plans are already underway to hold regional meetings to coincide with both the SIOP Asia and Africa meetings.

Fundraising and Sponsorship

Our primary source of funding is through membership fees and direct sponsorship of programs. The success of the Parents Helping Parents Fund (PHPF) campaign, demonstrates our members desire to support parents from developing countries to attend our annual conferences.

We are very grateful for generous sponsorships received over the past year both from within our membership and the wider international community for program specific needs and for components within our annual conference.

Secretariat

The executive committee is very grateful to The Netherlands Parent Group (VOKK) for hosting the secretariat on a pro bono basis.

Finances

The balance of funds of 31 December 2004 places ICCCPPO in a very strong position to be able to extend its programs, support more parents groups and reach out to those countries where children do not receive adequate care or no treatment at all.

Volunteers

ICCPO is indebted to those who provide precious time, energy and expertise. The organization could not exist without the dedication from these people. I would like to take this opportunity to thank the Board and those who serve on the various committees.

Conclusion

We have seen many faces of children with cancer and know they are no different from country to country. They are individuals fighting a disease that is as unique to them as their personality. Yet, it is these differences and these similarities that unite this organization in these goals -- that every child with cancer, regardless of financial or social class, race or native origin get access to the best possible treatment and medical care. And that their parents will have access to the information they require when making informed decisions about their child's treatment.

We promise to continue to work towards these goals – with our children's faces guiding us.



Simon Lala, Chair

On behalf of the Board of the ICCCPPO



STATEMENT OF REVENUE, EXPENSES AND FUND BALANCE

December 31, 2004 > to be adopted

	2004 (USD)	2003 (USD)
Revenue		
Membership Fees	19,842	16,693
Interest	2,459	1,315
Sponsorship	52,202	31,137
PHPF	12,629	11,419
Donations	6,280	1,115
Exchange Gains	11,755	9,694
Total Income	105,167	71,373

Expenses

Executive Meetings	5,367	5,320
Printing and Stationary	-	200
Audit Fees	500	500
AGA Scholarships	22,230	8,641
AGA Meeting Expenses	480	-
Regional Meetings	6,035	983
ICCD Expenses	2,152	7,964
Annual Report Expenses	3,750	2,901
Newsletter Costs	5,961	4,042
Bank Charges	287	711
Total Income	46,762	31,262

Excess of Income over Expenses	58,405	40,111
Fund Balance (beginning of year)	92,704	52,592
Fund Balance (end of year)	151,109	92,703