

THE INTERNATIONAL CONFEDERATION  
OF CHILDHOOD CANCER PARENT ORGANIZATIONS



# Annual Report 2006



On behalf of the Board, I am pleased to report that ICCCPO had another successful year delivering programs and developing of some exciting new initiatives.

### **Annual Conference**

The 2005 conference was held in Vancouver, Canada. More than 130 parents and survivors from around the world attended and participated in informative sessions and networking opportunities. Our sincerest thanks to the British Columbia Children's Cancer Parent Association for hosting the conference.

The highlight of this year's conference was the first year of "Through My Eyes: A Day in the Life of Children with Cancer Around the World". On 15 February, 2005, children in hospitals the world over, took pictures of people and things that reflect their thoughts and feelings about cancer and their treatments. The primary goal was to educate the public about childhood cancer and to demonstrate the vast differences in treatment between developed and developing countries. Thank you to Kids Cancer Care Foundation of Alberta for coordinating this unique project in recognition of International Child Cancer Day.

### **REGIONAL MEETINGS**

Successful regional meetings were held in Belgrade and Shanghai over the past year.

As envisaged, these meetings provided a forum for the members to address issues common to their regions. The Shanghai meeting celebrated the creation of two parent groups in mainland China. Detailed reports of our regional meetings are available through the secretariat.

### **MEMBERSHIP**

ICCCPO continues to grow in membership. At the last AGA 10 new members were admitted, bringing our total membership to 81 organisations from 58 countries.



### **SURVIVORS NETWORK**

A committee has now been in place for three years and has firmly established its mission and goals. Its current chairperson, Prudence Walker, has much to offer from her experience leading a very successful survivors group in New Zealand.

The success of the survivors network is evident in the increased number of survivors attending annual conferences offering lectures and workshops specific to their needs.

### **ST JUDE**

St Jude is the largest children's cancer centre in the world and the visit by members of our Executive Committee in January has provided a significant new relationship for ICCCPO. Three key areas for development include (1) learning from their experiences in setting up programs in developing countries; (2) their program experience in the USA for developed countries; and (3) the opportunities to cross-promote our organizations through the web and elsewhere.

Information provided by St Jude has directly helped the development of our World Child Cancer Foundation project.

### **SIOP**

Our relationship with SIOP continues to consolidate and we firmly believe our partnership is vital when it comes to lobbying and advocating for childhood cancer at the international level. The SIOP Board, under the leadership of Professor Tim Eden, has been very supportive of the role that ICCCPO plays.

### **INTERNATIONAL DRUG AGENCY (IDA)**

Access to cheaper paediatric drugs prompted a meeting with the IDA. We have learnt a lot about this not-for-profit organization and the processes involved in sourcing essential drugs for our members from developing countries.

## **Information and Communications**

Sharing information and networking are primary goals of ICCCPO and help empower our members to become stronger advocates in the fight against childhood cancer.

The ICCCPO website ([www.icccpo.org](http://www.icccpo.org)) has continued to be updated and provides a broad range of information on childhood cancer, parent groups and the activities of ICCCPO. A new innovation this year was to make the posters from the "Through My Eyes" project available on the site. There is a consistent number of visitors to the site of some 50,000 per year.

Over the past year, two comprehensive newsletters have been distributed. They contained information on the activities of different parent groups as well as other child cancer-related articles and reports from speakers at ICCCPO / SIOP conferences. To save costs, the Board decided to produce digital versions of the newsletter. The first issue for 2006 was published and distributed early this year.

## **Fundraising and Sponsorship**

The Board has recognised the need for fundraising at an international level to deliver more comprehensive programs in developing countries. We are grateful for the continued sponsorship from CLIC Sargent, the Lisa Thaxter Trust and the German Parent Group (D L F H). We also extend thanks to the Lance Armstrong Foundation for their generous sponsorship of the survivors program at the Vancouver conference.

The Parents Helping Parents Fund has now become a well-established source of funds for granting stipends to assist more delegates from developing countries to attend our annual conferences. We thank those member countries that so generously support this program.

### **UICC**

ICCCPO was invited to represent participants in the My Child Matters program, supporting projects in developing countries. The program has supported 14 projects in 10 countries, providing each with more than USD500,000. There is no doubt that this program will directly help families in the ten countries it supports and indirectly help families in other countries by promoting similar programs and developments. There is also some level of cooperation in World Cancer Day and International Cancer Day, both in February.

### **WORLD HEALTH ORGANISATION (WHO)**

During the year, meetings have been held with W.H.O. to seek more exposure for childhood cancer on the International scene. This year, we have been fortunate to secure guest speakers from the World Health Organisation. The Board is currently working on receiving endorsement from W.H.O. for our conference.

### **WORLD CHILD CANCER FOUNDATION (WCCF)**

Much progress has been made in developing the WCCF, which will become the funding arm of ICCCPO. All members have been consulted on the details of progress and the official launch is expected in the new year.



## SECRETARIAT

The Dutch Parent Organisation (VOKK) has continued to generously fund and undertake the work of the secretariat. As the workload increases, the Board is conscious of the need to fund the services of a part-time assistant.

## VOLUNTEERS

The Board maintains it is driven by a strong desire to make a difference in the lives of children with cancer and their families. We enjoy the work and look forward to another challenging year.

## Finances

The financial statements of ICCCPPO show that the organization stands in a sound financial position. With most financial transactions undertaken in Euros, the Board has decided this year to report in Euros as opposed to US dollars.



**Simon Lala, Chair**

On behalf of the Board of the ICCCPPO

## Statement of Revenue, Expenses and Fund Balance

December 31, 2005 >  
to be adopted

	2005 (EUR)	2004 (EUR)
<b>Revenue</b>		
Membership Fees	16,847	15,263
Interest	2,545	1,891
Sponsorship	24,101	40,156
PHPF	12,487	9,714
Donations	2,219	4,831
Exchange Gains	0	9,043
<b>Total Income</b>	<b>58,199</b>	<b>80,898</b>
<b>Expenses</b>		
Executive Meetings	4,437	4,128
Exchange Losses	2,571	0
Audit Fees	500	385
AGA Scholarships	23,348	17,100
AGA Meeting Expenses	1,807	370
Regional Meetings	7,403	4,642
ICCD Expenses	0	1,655
Annual Report Expenses	2,192	2,885
Newsletter Costs	2,683	4,585
Bank Charges	261	221
Advocacy & Lobbying	681	-
Legal	944	-
<b>Total Income</b>	<b>46,827</b>	<b>35,971</b>
<b>Excess of Income over Expenses</b>	<b>11,372</b>	<b>44,927</b>
<b>Fund Balance (beginning of year)</b>	<b>111,109</b>	<b>66,182</b>
<b>Fund Balance (end of year)</b>	<b>122,481</b>	<b>111,109</b>



# Members

	COUNTRY	TELEPHONE	EMAIL	WEBSITE
Fundación Natalí Dafne Flexer	ARGENTINA	54-11-4825-5333	edith@fundacionflexer.org	www.fundacionflexer.org
Society to Help Children with Cancer	ARMENIA	374-1-531442	badalyan@doctor.com	
Cancer Council of Tasmania	AUSTRALIA	61-03-6336-2249 61-409-847919 (m)	acraig@cancertas.org.au	www.cancertas.org.au
Childhood Cancer Support Inc.	AUSTRALIA	61 7 32524719	ceo@clcs.org.au	www.clcs.org.au
Kinder - Krebs - Hilfe (Dachverband)	AUSTRIA	43-1-402-8899	dachverband@kinderkrebshilfe.at	www.kinderkrebshilfe.at
ASHIC	BANGLADESH	88-02-8613594	ashic@bttb.net.bd	www.ashic.org
CLASS	BANGLADESH	88-031-657999	class@globalctg.net	
AFANIC	BOLIVIA	591-3-3442832	yolandaernst@hotmail.com	www.afanic.com
Heart for Kids with Cancer	BOSNIA HERCEGOVINA	387-33-638-381	srcezadjecubih@yahoo.com and hs@bih.net.ba	http://srcezadjecubih.tripod.com
NACC	BRAZIL	55-81-32679200	nacc@elogica.com.br	
Childhood Cancer Foundation Candlelighters Canada	CANADA	1-416-489 6440	dstones@candlelighters.ca	www.candlelighters.ca
BC Childhood Cancer Parents' Association	CANADA	1-604-875-2345 ext 6477	dmornar@cw.bc.ca	www.kidscancer.bc.ca
Kids Cancer Care Foundation of Alberta	CANADA	1-403-216-9210	wandzura@kidscancercare.ab.ca	www.kidscancercare.ab.ca
Candlelighters Childhood Cancer Support Programs Inc	CANADA	1-613-715-9157	candlelighters@rogers.com	www.candlelighters.net
Little Life Warrior Society	CHINA	852-2632-1144	childcancure@cuhk.edu.hk	www.childcancure.org.hk
Pau Kwong Wun Charitable Foundation	CHINA	852-2796-0818	info@pkwfoundation.org	
OPNICER	COLUMBIA	57-1-6112745	opnicer@opnicer.org	www.opnicer.org
Fondacion Paola Andrea Velasquez Vivas	COLUMBIA	57-3583434	fpaolaandrea@dinanet.net.co	members.ixp.net/ fundacionpaoloavelasquezvivas
Sanus	CROATIA	385-21-538-804	sanus@st.htnet.hr	www.sanus.hr
Zajedno	CROATIA	385-915771411	doria.verbic@ri.htnet.hr	
Grupo de Apoyo de Padres de Ninos Oncologicos "El Principito"	CUBA	53-7-23-3946	calderon@infomed.sld.cu	
Sdruží Šance	CZECH REPUBLIC	420-777-699-818	edvorakova@tiscali.cz	www.sancecz.org
Familier med kraeframte boern (FMKB)	DENMARK	45-86-9469 30	info@fmkb.dk	www.fmkb.dk
ASONIC	ECUADOR	593-2-250-6507	soveagro@easynet.net.ec	
Fundacion Esperanza de Vida	ECUADOR	593-4-281-4727	m_noles@hotmail.com	www.esperanzadevida.com
Alexandria Group of Childhood Cancer Care (AGCCC)	EGYPT	20-3-545-7334 20-3-421-8586	ysaad_eldin@yahoo.com	
ASAPAC	EL SALVADOR	503-257-7978	ceciliamoreno@telesal.net	
SYLVA	FINLAND	358-9-135-6866	syopa.lapset@sylva.inet.fi	
UNAPECLE	FRANCE	33-467-50-2836	unionparents@aol.com	
L'ENVOL	FRANCE	33-0-60 73-5858	lenvol@aol.com	www.l-envol.org
DLFH	GERMANY	49-228-68846-15	info@kinderkrebsstiftung.de	www.kinderkrebsstiftung.de
Floga	GREECE	30-1-74-85-000	f2001@otenet.gr	
IASO	GREECE			
Styrktarfelag Krabbameinssjúkra Barna	ICELAND	354-588-7555	skb@skb.is	www.skb.is
Sahayta Charitable Welfare Society	INDIA	91-172-2660168 93-161-20-808 (m)	sahayta@satyam.net.in	www.cancersahayta.org
Cankids....kidscan	INDIA	91-11-41663670/1 91-9811525745 (o)	poonambagai@cankidsindia.com	www.cankidsindia.com
Cancer Patients Aid Organisation	INDIA	91-22-24924000	Shubha.Maudgal@cpaaindia.org	www.cpaaindia.org
Indonesian Childhood Cancer Foundation (Yayasan Onkologi Anak Indonesia)	INDONESIA	62-21-568-1612/ 1570/1609 ext.2030	yoai2008@indosat.net.id	www.onkologianak.org / childhoodcancer.id.org
Society To Support Children Suffering From Cancer Known as "MAHAK"	IRAN	9821-22490544-7 9821-22451414	info@mahak-charity.org	www.mahak-charity.org
TCCUP	IRELAND	353-45-864115	michelle@tccup.com	www.tccup.com
The Barretstown Gang Camp	IRELAND	353-45-864115	ciara.casey@barretstowngc.ie	
CHAYIM - For Children With Cancer In Israel	ISRAEL	972-3-6120494	yifatba@012.net.il	

<b>Comitato Maria Letizia Verga</b>	ITALY	39-39-2333526	comitato.verga@pediatriamonza.it	
<b>Federazione Italiana delle Associazioni di Genitori di Oncoematologia Pediatrica</b>	ITALY	390-51-670 2086	s-cappello@libero.it	www.fiagop.it
<b>Children's Cancer Association of Japan</b>	JAPAN	81-3-5825-6311	nozomi@ccaj-found.or.jp	www.ccaj-found.or.jp
<b>Asian Children's Care League (ACCL)</b>	JAPAN	81-3-3663-1369	accl@accl.jp	www.accl.jp
<b>Korean Association for Children with Leukemia and Cancer</b>	KOREA	82-2-37754112	miokcho@unitel.co.kr	www.soaam.or.kr
<b>Latulan Childhood Cancer Society</b>	LATVIA	371-294-728		
<b>Paguoda</b>	LITHUANIA	370-659 77959	info@paguoda.org	www.paguoda.org
<b>Een Häerz fir kriibskrank Kanner asbl</b>	LUXEMBURG	352-514 629 352-61-230606 (m)	icccpo@kriibskrankanner.lu	www.kriibskrankanner.lu
<b>Peperutka</b>	MACEDONIA	389-2 323-1384	peperutka_2003@yahoo.com	www.peperutka.org.mk
<b>Children's Cancer Club</b>	MALAWI	674-333 ext. 3260	emolyneux@malawi.net	
<b>AMANC</b>	MEXICO	52-55-5513-7111	amanc1@amanc.org	www.amanc.org
<b>L'Avenir</b>	MOROCCO	212-37-754174	avenir.2@iam.net.ma	www.almoustakbal.org
<b>Vereniging 'Ouders, Kinderen en Kanker' (VOKK)</b>	NETHERLANDS	31-302422944	mc.naafs@vokk.nl / bureau@vokk.nl	www.vokk.nl
<b>Child Cancer Foundation</b>	NEW ZEALAND	64-9-373-3670	ceo@childcancer.co.nz	www.childcancer.co.nz
<b>Asociacion de Padres de Ninos Con Leucemia y Cancer</b>	NICARAGUA		drcardenas@yahoo.com	
<b>Stotteforeningen for Kreftsyke Barn (SKB)</b>	NORWAY	47-22866741	skb@kreftforeningen.no	www.kreftsyke-barn.no
<b>MITA'I Asociacoón de de Padres para ayuda a niños con cancer</b>	PARAGUAY	595-21-600-234	mitai@conexion.com.py	
<b>Cancer Warriors Foundation Inc</b>	PHILIPPINES	63-2-5514588	jauste@pacific.net.ph	www.c-warriors.org
<b>Acreditar</b>	PORTUGAL	351-21-7221150	acreditar@mail.telepac.pt	
<b>P.A.V.E.L.</b>	ROMANIA	40-1-344-2885	pavel_romania@hotmail.com / pavel_romania@yahoo.com	www.asociatiapavel.home.ro and www.fiiaturidenoi.org
<b>Novosibirsk City Foundation for Aid to Invalid Children With Oncohematologic Diseases</b>	RUSSIA	3832-46-48-31	proskuryakova@mail.ru	
<b>CAPAC</b>	RUSSIA	7-812-571-74-83	childrencancer@peterlink.ru	www.deti.blood.ru
<b>Triendinstvo</b>	RUSSIA	8-818-42-37749	ninacost@atnet.ru	
<b>ISKORKA</b>	RUSSIA	7-3512-340301	ohc@fromru.com; vera1@fromru.com	
<b>Regional Charity Organization for helping Children in behalf of St. Elizabeth</b>	RUSSIA	78442942585 79023119919	tony_m02@mail.ru	
<b>NURDOR</b>	SERBIA	381-11-324-61-69	office@nurdor.org.yu	www.nurdor.org.yu
<b>Children's Cancer Foundation</b>	SINGAPORE	65-6835-6465	admin@ccf.org.sg	www.ccf.org.sg
<b>CHOC National</b>	SOUTH AFRICA	27-11-486-1212	national@choc.org.za	www.choc.org.za
<b>Federación Española de Padres del Niños con Cáncer</b>	SPAIN	34-93-850-5344	federacion@cancerinfantil.org	www.cancerinfantil.org
<b>Barncancerfonden</b>	SWEDEN	46-8-584-209-00	info@barncancerfonden.se	www.barncancerfonden.se
<b>Kinderkrebshilfe Schweiz</b>	SWITZERLAND	41-32-637-3085	info@kinderkrebshilfe.ch	www.kinderkrebshilfe.ch
<b>LÖSEV</b>	TURKEY	90-312-447-0660	losev@losev.org.tr	www.losev.org.tr
<b>Mercy Mission "Overcoming"</b>	UKRAINE	38-652-511-613	novitsky@simfi.net	hematolog.vinchi.ru / hematolog.simfi.net
<b>Charitable Fund VIDEN</b>	UKRAINE	38-5447-712-87	viden@sm.ukrtel.net	
<b>NACCP0</b>	UNITED KINGDOM	44-173-755 5411	ro@naccpo.org.uk	www.naccpo.org.uk
<b>UKCCSG</b>	UNITED KINGDOM	44-116-249 4460	ukccsg@le.ac.uk	www.ukccsg.org
<b>CLIC Sargent</b>	UNITED KINGDOM	44-208 752 2800	care@sargent.org	www.sargent.org and www.clic.org
<b>Candlelighters Childhood Cancer Foundation</b>	USA	1-301-962-3520	staff@candlelighters.org	www.candlelighters.org
<b>Asociacion Venezolana de Padres de Ninos con Cancer Servicio de Oncologia</b>	VENEZUELA	058-0212-574-3601	rosybriceno@cantv.net/fumigo@cantv.net	www.fncancer.org.ve