ANNUAL REPORT 2008-09

The board is proud to share the success of the ICCCPO activities and programmes over the past year.

Message from the Chair

Welcome to our 2008-09 annual report. 2009 marks ICCCPO's 15th anniversary. To celebrate this milestone we have published a "Book of Hope" - stories from survivors who were diagnosed exactly 15 years ago. It seemed to us the best way to celebrate what ICCCPO is all about.

Established in 1994, ICCCPO has now become the most prestigious international non-medical childhood cancer in the world, with more than 118 members and significant representation in all continents. The success of ICCCPO is to a large extent due to the driving force of past and present Board members and the great leadership of our past Chairs: Jesús Maria Gonzalez Marín, Kurt Hansen, Mark Chesler, Marianne Naafs-Wilstra, Simon Lala and Geoff Thaxter.

Though this is my first year as Chairman, I am very fortunate to have had a determined, energetic and passionate predecessor, Geoff Thaxter, who contributed valuable leadership to the Confederation. The Board and I will continue to develop strategies and move forward with the growth of ICCCPO and the betterment of children with cancer in the world in mind.

The tremendous increase of membership in the past years shows that more and more people are working with enthusiasm for the benefit of children with cancer and their families around the world. Yet there is still a lot of work to do to achieve ICCCPO's mission: "to improve access to the best possible treatment and care for children with cancer everywhere in the world".

To close the gap that still exists between the wealthy and the low income countries, the Board and I will keep on working towards narrowing the imbalances that exist. This includes fostering a "we care - we share" culture; developing continental and regional work; ensuring the continuity of ICCCPO; building alliances with all those involved in the field; advocating the needs of families at an international level; and supporting World Child Cancer, the organisation initiated by ICCCPO, which provides funding to help children with cancer in developing countries.

Let's all work together to achieve these goals.

Benson Pau Chairman

Annual Conference

The 2008 Annual Conference was held in Berlin, Germany at the end of October along with the SIOP conference with more than 2000 delegates attended the meeting. Amongst these were 100 parents from 41 countries and 40 survivors from 18 countries. The conference for parents and survivors consisted of a half-day workshop and three full days filled with presentations on various topics. The conference is an important means for sharing knowledge and experiences from all over the world.

A new initiative at the conference this year was Meet-the-Experts session organized for parents and survivors. These sessions were highly appreciated and will be part of the future conference programmes.

We would like to thank the organising committee – Anders Wollmén, Anita Kienesberger, Gerlind Bode, Prudence Walker-Cuttance and their teams for their enormous effort and time they put into making this conference possible. We are also grateful for the generous sponsorships we received from several ICCCPO members.

Annual General Assembly

At the AGA in Berlin, Julian Cutland from South Africa stepped down after serving the Board for seven years. Julian remains active in communications, especially our website. We sincerely thank him for his contribution to the Board and his efforts in Africa. Kenneth Dollman from South Africa was elected as a new Board member. Geoff Thaxter who was elected as chairman in Mumbai in 2007 sadly passed away in August 2008 and Benson Pau was elected as his successor. Anders Wollmén became Vice-Chair.

Sadie Cutland, Marianne Naafs-Wilstra and the late Geoff Thaxter were appointed as **honorary members** in acknowledgement of their tremendous contribution to ICCCPO, Jesús Maria Gonzalez Marín and Gerlind Bode were also officially recognised as honorary members on this occasion.

Executive Committee Meeting

The Board met on two occasions: in October 2008 in Berlin, Germany and then again in March 2009 in Werkhoven, The Netherlands.

Membership

At the Annual General Assembly in Berlin, fourteen new organisations were adopted as new members (ten full and four associate members), eight of these are from new countries and two in Sweden have merged. This brings our current membership to 118 members from 73 countries. With Ethiopia, Ghana and Zimbabwe becoming members, we have almost doubled our membership on the African continent. Other new countries are Chile, Nepal, Syria, Tonga and Trinidad.

Regional Meetings & Activities

Africa

In Africa the focus over the past year has been to identify and contact individuals (be they parents or sympathetic medical experts) from countries where full treatment or partial treatments for childhood cancer are offered at treatment centres and from countries where no parent group exists. The approach has then been to engage these individuals in conversations to encourage them to find like-minded or suitable individuals to establish a parent group. Once the groups have been identified, practical assistance, motivation, support, and in some cases, visits have taken place to facilitate the formation of parent groups.

Since October 2008, new parent groups have been established in Mozambique, Namibia, and Malawi. A regional meeting is being planned for March 2010 in Akra, Ghana.

Asia

ICCCPO Asia Regional Meeting was held in Beirut, Lebanon April 2 to 3, 2009 with excellent support by the local groups. About 120 participants attended the meeting, including six delegates from other Arab countries.

The meeting proved to be very helpful to members in the region and enabled them to not only share and compare their work for childhood cancer but to also motivate one another. Lebanon is a good example of the "therapeutic alliance" that can exist between medical professionals, parent groups and supporting NGOs in the Arab World. Hopefully this will lay the ground for more parent groups in this area to support more families.

Europe

In 2008, parents from countries of former Yugoslavia designed a website, www.kids-cancer.info, with contact details and information on all children cancer foundations and paediatric oncology centres in Serbia, Slovenia, Croatia, Bosnia & Herzegovina and Macedonia.

The results of ICCCPO Board representative Irina Ban's commitment to organizing regional meetings for countries of the former Soviet Union and former Yugoslavia is starting to show. Progress has been made in developing a therapeutic alliance to carry out ICCCPO's mission to strive for the best possible treatment and care for children with cancer in these areas.

To keep up the momentum, two regional meetings are to be held in Kiev, Ukraine and in Skopje, Macedonia in 2009.

Latin America

Board representative Edith Grynszpancholc visited Brazil, Paraguay, Colombia, Costa Rica and Perú in 2008 to carry out ICCCPO regional work.

There are a lot of groups in the LATAM region supporting childhood cancer at various levels but most of them do not work together on a national basis. The situation began to change when the Chilean groups starting to cooperate after attending the recent regional meeting in Ecuador. Later, six Columbian groups cooperated in a joint effort to increase public awareness and influence the politics surrounding childhood cancer.

Hopefully the next LATAM regional meeting in Guadalajara 2010 will go further to achieving mutual goals.

Communications & Information

Newsletter

Sarah Talbott-Williams from CLIC Sargent Cancer Care for Children in the United Kingdom delivered two volumes of the newsletter. She has given the newsletter a new look. The newsletters will come out in a new digital format, as an enewsletter from mid-2009.

Publication

"Your Group is not Alone"

The handbook was finalized and sent to all members and contacts. This manual is intended to incorporate the experiences of existing groups and to provide ideas and advice to people who are starting new groups to support children with cancer, especially in developing nations. Thanks to Julian Cutland for his work in producing this handbook.

"Book of Hope"

On the occasion of ICCCPO's 15th anniversary Gerlind Bode, with the help of Marianne Naafs-Wilstra, compiled the "Book of Hope" with fifteen stories from fifteen countries celebrating fifteen years of ICCCPO. When asking our members for stories we realized that it was much harder to find survivors treated 15 years ago from countries in Latin America, Asia and Africa, which seems to show that 15 years ago, survival rates were much lower in many of the countries from these continents and thus, fewer "success stories" were available. We managed, however, to receive a fairly even distribution of interesting reports from different continents and believe they reflect the situation across the world. The stories in this booklet are wonderful examples of courage, faith and gratitude. In different words and ways they tell us about the patients' experiences, their struggle to overcome the disease and eventually take control of their lives again. These young people are grateful for being given a "second chance" and thank all those who helped them along the way: the doctors, the nurses, their families and friends. Their success stories represent what ICCCPO is striving for. The book will be sent to all members.

Website

The ICCCPO website will again undergo an intensive revamp in 2009. This service is provided free of charge by Onlinebase, an IT-company based in The Netherlands. The number of visitors to the site has been fairly steady at about 3,500 per month.

Sponsorship

The Board extends its gratitude to all those members and individuals who have contributed by way of services-in-kind or by making financial supports, particularly the contributions of German Kinderkrebsstiftung, Een Häerz fir kriibskrank Kanner Luxembourg, Swedish Childhood Cancer Foundation and CLIC Sargent Cancer Care for Children United Kingdom for their financial support of the 2008 ICCCPO Annual Conference held in Berlin.

We encourage sponsorship to ICCCPO to make our vision "we care – we share" a reality. The on-going success of ICCCPO can be attributed to your generosity. Please contact the Secretariat on icccpo-secretariat@vokk.nl

Parents Helping Parents Fund

The Parents Helping Parents Fund (PHPF) remains important to support delegates from less privileged countries to attend the ICCCPO meetings. We are extremely grateful to those members who supported the PHPF and thus made our vision of sharing a reality.

Secretariat

The Dutch Parent (VOKK) has continued to generously undertake the work of Secretariat to ICCCPO with Dr. Patty Brouwer as part-time assistant.

Collaboration Programmes

My Child Matters

My Child Matters has been a highly successful programme organised by UICC with the support of Sanofi Aventis. No other single programme has provided so much support for child cancer programmes in so many countries. ICCCPO has been delighted to be part of this work. Our thanks go to UICC and Sanofi Aventis and to all our colleagues on the My Child Matters Board who have made this a success.



World Child Cancer

World Child Cancer No child should suffe

In 2008-09 the charity launched its first projects. The first project supported is in Malawi, which is twinning with EMMA Children's Hospital / AMC University in Amsterdam. The second is in Colombia, which is twinning with the Dana-Farber Cancer Institute, part of Harvard University, in Boston. In order to achieve long-term sustainable success, projects are carefully selected by our medical trustees who employ rigorous criteria. The charity plans to initiate another six projects in 2009-10 and hopes to have a total of 16 projects in operation by 2012. Each project receives financial support of £30,000 to £50,000 a year for five years with the long-term objective of developing sustainability. Seed-funding at this level makes a significant impact on the number of children who survive and go on to lead normal, healthy lives.

Financially, World Child Cancer is on target to raise £300,000 in 2009.

Three key members of ICCCPO have been trustees of World Child Cancer since its inception: Simon Lala and Marianne Naafs-Wilstra, both past chairs. The current chair of ICCCPO, Benson Pau, is also a trustee of World Child Cancer. This assures ICCCPO's ownership of the charity.

World Child Cancer Foundation has shortened its name to World Child Cancer and has also revised its logo. The charity's registered address has been changed to Carldane Court, Bromley Lane, Much Hadham, Herts SG10 6HU, United Kingdom.

Statement of Revenue, Expenses & Fund Balance As at 31 December 2008

	2008 (EUR)	2007 (EUR)
Revenue Membership Fees Interest Sponsorship PHPF Donations WCCF Sponsorship CHILDHOPE	24,673 4,503 19,760 15,903 158 9,500	24,300 3,671 8,589 8,739 6,313 46,251 36,155
Total Income	74,497	134,018
Expenses		
Executive Meetings Secretariat Audit Fees AGA Scholarships AGA Meeting Expenses Regional Meetings WCCF Expenses Annual Report Expenses Bank Charges Advocacy & Lobbying General Expenses CHILDHOPE Expenses	9,147 5,000 500 15,100 14,151 11,802 791 800 1,106 9,792	4,124 380 13,054 7,435 13,145 23,653 2,097 909 954 257 26,064
Total Expenses	68,189	92,072
Net Surplus for the year Less transfers to reserves (net) Net Surplus (deficit) for year	6,308 7,208 -900	41,946 33,579 8,367
Fund Balance, Beginning of year Fund Balance, End of year Conference Reserve CHILDHOPE Reserve	94,743 93,843 7,500 9.817	86,375 94,742 10,099
Total al Funds	111,160	104,841

^{*}figures subject to audit

Executive Committee

Benson Pau Chairman, China

Anders Wollmén Vice Chairman, Sweden

Kenneth Dollman Secretary, South Africa

Simon Lala Treasurer, New Zealand

Anita Kienesberger Member, Austria

Edith Grynszpancholc Member, Argentina

Ira Soelistyo Member, Indonesia

Irina Cepinac Ban Member, Serbia

Honorary Members

Jesús Maria Gonzalez Marín Spain

Gerlind Bode Germany

Sadie Cutland South Africa

Marianne Naafs-Wilstra The Netherlands

Secretariat

Marianne Naafs-Wilstra Email: icccpo-secretariat@vokk.nl

This Annual Report was produced and sponsored by Pau Kwong Wun Charitable Foundation (Hong Kong, China).

Members	Country	Website or Email
Fundación Natalí Dafne Flexer	ARGENTINA	www.fundacionflexer.org
Society to Help Children with Cancer	ARMENIA	badalyan@doctor.com
Cancer Council of Tasmania	AUSTRALIA	www.cancertas.org.au
Childhood Cancer Support Inc.	AUSTRALIA	www.clcs.org.au
Kinder - Krebs - Hilfe (Dachverband)	AUSTRIA	www.kinderkrebshilfe.at
ASHIC - Foundation for Childhood Cancer	BANGLADESH	www.ashic.org
Children Leukaemia Assistance & Support Services (CLASS)	BANGLADESH	www.classbd.org
Asociacion de Familiares y Amigos de Ninos con Cancer (AFANIC)	BOLIVIA	www.afanic.com
The Heart for Kids with Cancer in FbiH	BOSNIA HERCEGOVINA	srcezadjecufbih.tripod.com
Nucleo Apaio Crianca con Cancer (NACC)	BRAZIL	www.nacc.org.br
Caio Roberts Society	BRAZIL	joroberts@uol.com.br
Childhood Cancer Foundation Candlelighters Canada	CANADA	www.candlelighters.ca
BC Childhood Cancer Parents' Association	CANADA	www.bcccpa.org
Kids Cancer Care Foundation of Alberta (KCCF)	CANADA	www.kidscancercare.ab.ca
Candlelighters Childhood Cancer Support Programs Inc	CANADA	www.candlelighters.net
Kids with Cancer Society Northern Alberta	CANADA	www.kidswithcancer.ca
Fundacion Nuestros Hijos	CHILE	www.fnh.cl
Little Life Warrior Society	CHINA	www.childcancure.org.hk
Pau Kwong Wun Charitable Foundation	CHINA	www.pkwfoundation.org
Guangzhou Childhood Cancer Parents Group	CHINA	www.jiazhanghui.org.cn
Colombian Childhood Cancer Parents Organization & Relationship Diseases (OPNICER)	COLUMBIA	www.opnicer.org
Fondacion Paola Andrea Velasquez Vivas	COLUMBIA	members.ixp.net
Sanus Club of Parents whose children are suffering from malignant diseases	CROATIA	www.sanus.hr
Zajedno	CROATIA	doria.verbic@ri.htnet.hr
Firefly	CROATIA	www.krijesnica.hr
Grupo de Apoyo de Padres de Ninos Oncologicos "El Principito"	CUBA	calderon@infomed.sld.cu
Sdruží Šance	CZECH REPUBLIC	www.sancecz.org
Familier med kraeframte boern (FMKB)	DENMARK	www.fmkb.dk
Fundacion Amigos contra el cancer Infantil, Inc (FACCI)	DOMINICAN REPUBLIC	www.facci.org.do
Asociacion Ecuatoriana de Padres de Ninos con cancer (ASONIC)	ECUADOR	soveagro@easynet.net.ec
Fundacion Esperanza de Vida	ECUADOR	www.esperanzadevida.com
Sol e Vida	ECUADOR	www.solyvida.info
Alexandria Group of Childhood Cancer Care (AGCCC)	EGYPT	ysaad_eldin@yahoo.com
Parents Committee of the Oncology Service (ASAPAC)	EL SALVADOR	cdemoreno@gmail.com
Mathiwos Wondu - YeEthiopia Cancer Society	ETHIOPIA	www.mathycancersoc.org
Sylva Ry	FINLAND	www.sylva.fi
Union Nationale des Assoc de Parents d'Enfants atteints de Cancer ou Leucemie (UNAPECLE)	FRANCE	unionparents@aol.com
L'Envol	FRANCE	www.lenvol.asso.fr
Deutsche Leukamie-Foruschungshilfe	GERMANY	www.kinderkrebsstiftung.de
Ghana Parents Association for Childhood Cancers (GHAPACC)	GHANA	lornarenner@gmail.com
Greek Parents Association of Children with Cancer (FLOGA)	GREECE	www.floga.org.gr
IASO	GREECE	iaso@oternet.gr
Európai Támogatási Egyesület a Rákos Gyermekekért	HUNGARY	www.euroonko.de
Styrktarfelag Krabbameinssjúkra Barna	ICELAND	www.skb.is
Sahayta Charitable Welfare Society	INDIA	www.cancersahayta.org
Cankidskidscan	INDIA	www.cankidsindia.org
Cancer Patients Aid Organisation	INDIA	www.cpaaindia.org
Indonesian Childhood Cancer Foundation (Yayasan Onkologi Anak Indonesia)	INDONESIA	www.onkologianak.org
Care for Cancer Kids Foundation	INDONESIA	www.ykaki.org
Care for Children with Cancer Foundation (Yayasan Peduli Anak Kanker) MANADO	INDONESIA	www.onkologianak.org
Society To Support Children Suffering From Cancer Known as "MAHAK"	IRAN	www.mahak-charity.org
Teenage and Childhood Cancer Uniting Parents (TCCUP)	IRELAND	www.tccup.com
The Barretstown Gang Camp	IRELAND	www.barretstown.org
CanTeen Ireland	IRELAND	www.canteen.ie
CHAYIM - For Children With Cancer In Israel	ISRAEL	www.hayim.org.il
Comitato Maria Letizia Verga	ITALY	www.comitatomarialetiziaverga.it
Federazione Italiana Associazioni Genitori Oncoematologia Pediatrica (FIAGOP)	ITALY	www.fiagop.it
Associazione Bianca Garavaglia	ITALY	www.abianca.org
Fondazione Cure2Children	ITALY	www.cure2children.org
Children's Cancer Association of Japan	JAPAN	www.ccaj-found.or.jp
Asian Children's Care League (ACCL)	JAPAN	www.accl.jp
Association CHANCE - Children Against Cancer	LEBANON	www.chancelebanon.org
Paguoda - Lithuanian Society of Children with Onkohematological Diseases	LITHUANIA	www.paguoda.org
Een Häerz fir kriibskrank Kanner asbl	LUXEMBURG	www.kriibskrankkanner.lu
Peperutka	MACEDONIA	www.peperutka.org.mk

Members	Country	Website or Email
Children's Cancer Club	MALAWI	emolyneux@malawi.net
Asociacion Mexicana de Ayuda a Ninos con Cancer (AMANC)	MEXICO	www.amanc.org
Centro de apoyo a ninos con cancer (CANICA)	MEXICO	www.casacanica.org
Association L'Avenir	MOROCCO	www.almoustakbal.org
Noujoum - Association de Parents Pour le soutien aux enfants malades	MOROCCO	www.noujourn.org
Cancer Society	NEPAL	www.cancersocietynepal.org.np
Vereniging Ouders, Kinderen en Kanker' (VOKK)	NETHERLANDS	www.vokk.nl
Child Cancer Foundation	NEW ZEALAND	www.childcancer.co.nz
Asociacion de Padres de Ninos Con Leucemia y Cancer	NICARAGUA	drcardenas@yahoo.com
Children living with cancer	NIGERIA	www.clwcf.org
Stotteforeningen for Kreftsyke Barn (SKB)	NORWAY	www.kreftsyke-barn.no
Cured Cancer Patients Society	PAKISTAN	www.ccpsociety.com
Asociacón de Padres para ayuda a niños con cancer (MITA'I)	PARAGUAY	mitai@conexion.com.py
Associade de Padres de Ninos con Cancer (ASPANION)	PERU	www.aspanion.org
Cancer Warriors Foundation Inc	PHILIPPINES	www.c-warriors.org
Acreditar - Portuguese Association of Parents and Friends of Children with Cancer	PORTUGAL	www.acreditar.org.pt
Primind Ajutor, Viata Este Luminoasa (PAVEL)	ROMANIA	www.asociatiapavel.home.ro
Nadejda	RUSSIA	www.oo-nadejda.com
Children & Parents Against Cancer (CAPAC)	RUSSIA	www.detiblood.ru
Triendinstvo	RUSSIA	ninacost@atnet.ru
Iskorka	RUSSIA	mopob@chel.surnet.ru
Regional Charity Organization for helping Children on behalf of St. Elizabeth	RUSSIA	www.saint-elizabeth.ru
The Charity Fund The Holiday of the Life	RUSSIA	www.holilife.ru/blago
Association pour le Soutien aux Enfants atteints de Cancer (ASEAC)	SENEGAL	nourcancer@yahoo.fr
Nacionalo Udruzenje Roditelja Dece Oblele ud Raka (NURDOR)	SERBIA	www.nurdor.org.yu
Children's Cancer Foundation	SINGAPORE	www.ccf.org.sg
Childhood Cancer Foundation South Africa (CHOC)	SOUTH AFRICA	www.choc.orq.za
Korean Association for Children with Leukemia and Cancer (KACLC)	SOUTH KOREA	www.soaam.or.kr
Federación Española de Padres del Niños con Cáncer	SPAIN	www.cancerinfantil.org
Barncancerfonden	SWEDEN	www.barncancerfonden.se
Barncancerföreningen Norra	SWEDEN	www.barncancerforeningen.se/norra
Barncancerföreningen Södra	SWEDEN	www.barncancersyd.com
"Barncancerföreningen i Stockholmsregionen"	SWEDEN	www.barncancerforeningen.se/stockholm
Barncancerföreningen i Uppsalaregionen	SWEDEN	www.barncancerforeningen.se/uppsala
Barncancerföreningen Gävle-Dala	SWEDEN	www.barncancerforeningen.se/gavledala
Kinderkrebshilfe Schweiz	SWITZERLAND	www.kinderkrebshilfe.ch
BASMA Children's with Cancer Support Association	SYRIA	www.basma-syria.org
Child Cancer Foundation of Tonga	TONGA	ccft@qmail.com
The Just Because Foundation	TRINIDAD & TOBAGO	justbecause@mail.tt
Losemili Cocuklar Vakfi (LÖSEV)	TURKEY	www.losev.org.tr
Mercy Mission "Overcoming"	UKRAINE	hematolog.vinchi.ru
Charitable Fund VIDEN	UKRAINE	viden@sm.ukrtel.net
David Deacon Charity Institution	UKRAINE	seelig-david@t-online.de
Childhood Cancer Foundation "CRAB"	UKRAINE	www.krab.org.ua
Ukrainian Cheritable Fund "Zaporuka"	UKRAINE	www.zaporuka.com.ua
National Alliance of Childhood Cancer Parents Organisations (NACCPO)	UNITED KINGDOM	www.naccpo.org.uk
Children's Cancer And Leukaemie Group (CCLG)	UNITED KINGDOM	
	UNITED KINGDOM	www.cclg.org.uk
CLIC Sargent Cancer Care for Children		www.clicsargent.org.uk
Wilms at Home Candlelighters Childhood Cancer Foundation	UNITED KINGDOM	www.wilmsathome.org.uk
	USA VENEZUELA	www.candlelighters.org
Asociacion Venezolana de Padres de Ninos con Cancer (ASOVEPANICA)	VENEZUELA	www.fncancer.org.ve
Children's Cancer Palief	VIETNAM	huongtm@dng.vnn.vn
Children's Cancer Relief	ZIMBABWE	info@kidzcan.co.zw

118 member organisations in 73 countries