



ICCCPO

**ANNUAL
REPORT**
2009 - 2010

**we care,
we share**

THE INTERNATIONAL CONFEDERATION
OF CHILDHOOD CANCER PARENT ORGANISATIONS



www.icccpo.org

Message from Chair

I am pleased to present the ICCCPPO Annual Report 2009-2010. It has been another motivating and fruitful year with fast growing membership, as well as remarkable events, activities and achievements at all levels. All ICCCPPO Executive Board Members and Advisors have been working enthusiastically to nurture the formation and growth of parent groups so as to narrow the gap between resource-rich and resource-limited countries for the improvement of childhood cancer treatment and care.

I am thrilled and proud to report that ICCCPPO attained Special Consultative Status with the Economic and Social Council (ECOSOC) of the United Nations in July 2010. This paves the way for ICCCPPO to achieve international recognition. On 15th February 2010 International Childhood Cancer Day (ICCD), ICCCPPO issued a joint statement with the International Union Against Cancer and World Child Cancer to promote awareness of childhood cancer. We shall keep working on international advocacy and hopefully one day ICCD will become an official date on the global cancer agendas.

Being the initiator of World Child Cancer, ICCCPPO organised Global Fundraising 2010 for the first time to coincide with ICCD. Sixteen member organisations took part in the event and raised €12,000 to assist World Child Cancer programs in resource-limited countries. Much still needs to be done to deal with the inequality of childhood cancer treatment and care in resource-limited countries.

One of our focuses in the coming year will be to develop more regional representatives who are willing and able to assist with regional work in order to achieve this mission of ICCCPPO and to support the continuity of ICCCPPO.

To all our volunteers, ICCCPPO members and committees, please accept my sincere gratitude for your high unwavering involvement and dedicated support. I look forward to your continuous cooperation in the future.

Sincerely,


Benson Pau
Chairman

Annual Conference

The 2009 annual conference in Sao Paulo, Brazil, was a good example of our motto "We care, We share". Together with all other participants at this 41st SIOP Conference, we experienced a high quality, well organised conference. This was made possible through the hard work of the local organising committee, all the speakers, chairs of sessions and of course our delegates. Special thanks to Anders Wollmén and Anita Kienesberger for organising the ICCCPPO annual conference for the second time.

Annual General Assembly

At the AGA in Sao Paulo, Irina Ban from Serbia, and Benson Pau from Hong Kong SAR, China were re-elected onto the Executive Committee for another 3 year term. Val Figliuzzi from Canada was elected as a new member. We welcome Val as the representative for North America.

Christina McIver and Professor Tim Eden were conferred as Honorary Members of ICCCPPO for their outstanding

contribution to the cause of children with cancer and ICCCPPO.

Executive Committee Meeting

An ICCCPPO EC meeting was held in Sao Paulo, Brazil, as usual just prior to the annual conference in October 2009. The mid-year EC meeting was held in Belgrade, Serbia in March 2010 in conjunction with Serbia National Parent Group AGA. Not only was it a constructive meeting, but also a great opportunity to support the growth of the local parent groups.

Membership

At the Annual General Assembly in Sao Paolo, fifteen new organisations were adopted as new members (seven as full and eight as associate members). Five of these are from new countries. We lost one member in Ireland which had been disbanded. This brings our membership to 132 member organisations from 78 countries.

Regional Meetings & Activities

Africa

In Africa, a focus area continues to be identifying and then contacting individuals, be they parents or sympathetic medical experts, from countries where full treatment or aspects of treatment for childhood cancer is offered at treatment centres, but where no parent group exists. To this end approaches have been made to a number of potential groups where practical assistance, motivation, support and in some cases visits have taken place to facilitate the formation of parent groups. Cooperation and

networking opportunities have been established with World Child Cancer, UICC, AfrOx, Children in Crossfire and the LiveStrong Foundation to further the aims of ICCCPPO in Africa.

Since October 2009, with Kenneth Dollman's effort, new parent groups have been established in Sierra Leone, Kenya and Uganda. Potential new groups could be established soon in Tanzania, Nigeria, Cameroon and Zambia. Another focus area is to establish successful twinning projects in

Africa. Such projects are operational in a number of African countries. It is a sincere hope that such projects expand to include many more African countries where children with cancer can benefit.

A regional meeting of ICCCP Africa was held in Akra, Ghana during March 2010. This was made possible through the expert organisation of Dr Lorna Renner and the local organising committee, supported by Mr Kwame Aveh.

Asia

The first China National Parent Groups meeting was held in July 2009 in Guangzhou with the support of ICCCP. It was a great success. Parent groups, childhood cancer foundations and other medical professionals from nine main cities participated, despite the fact that the development of parent groups in China is still in its early stages.

In 2010, Benson Pau visited parent groups in the Philippines, Indonesia and Vietnam to support the growth of regional parent groups. Both local ICCCP members in the Philippines and Indonesia arranged meetings with officers of health ministries. It was a good opportunity to raise awareness and advocate for childhood cancer at governmental level.

On behalf of ICCCP, Benson Pau attended UICC's World Cancer Congress 2010 and World Cancer Leaders' Summit in Shenzhen, China in August 2010.

Europe

Organised by Gerlind Bode, Marianne Naafs-Wilstra and Anita Kienesberger, all European ICCCP members were invited to the first information meeting on all EU sponsored projects in which ICCCP is a partner. Unfortunately, this meeting which had been scheduled for a mid-April weekend was unexpectedly hampered by the cloud of volcanic ash from the Icelandic volcano. So, only those who could travel by train or car were able attend the meeting in Bonn, Germany. Representatives of the projects CHILDHOPE, EPOC and ELTEC informed the ICCCP delegates about the aims and possibilities of these projects. A proposal for a new project titled ENNCA was introduced. During these presentations, delegates soon realized that research on the treatment and care of children with cancer has become much more international within the European context.

Communications & Information

Newsletter & Website

The new ICCCP website is still under construction – unfortunately for quite a while already. As it is intended to change the newsletter into a fully digital version connected to the website, it was not possible to distribute any new edition of the newsletter during the past year.

Sponsorship

The board extends its gratitude to all those members who have contributed by way of services-in-kind or by making financial contributions. Special thanks to Pfizer Argentina and Barncancerfonden Sweden for their donation for the annual meeting in Sao Paolo as well as to Pau Kwong Wun Foundation in Hong Kong for their support of regional work.

The ongoing success of ICCCP can be attributed to your generosity. If you want to support our work, please contact the Secretariat for details.

The 5th Regional meeting of Childhood Cancer Parent Organisations from former Yugoslavia countries was held in Ljubljana, Republic Slovenia in June 2010, with the support of ICCCP. The meeting was successfully organised by Irina Ban and Slovenian Childhood Cancer Parent Organisation (SLoDRS), with participation of parents, survivors and physicians from 5 countries and of great importance the presence of local authorities.

Latin America

Edith Grynspancholic has made several visits to La Paz, Cochabambay Santa Cruz de la Sierra, Bolivia, where she met some new organisations and other individuals helping children with cancer. The idea in Latin America is to make allgroups work towards creating a national perspective to improve the outcomes of children with cancer in their countries.

In Santiago, Chile, she has been invited to talk about networking, during their Second National Meeting of CCF. She was also invited to give a talk about networking and improving quality of life in children with cancer in Tijuana, Mexico, during their National Haematology/ Oncology Meeting. Just before the ICCCP annual conference in Sao Paulo, Brazil, she also organised a Latin-American Regional Meeting with the Society of Latin American Pediatric Oncology (SLAOP).

North America

As a new board member, Val Figliuzzi has attempted to connect with groups across North America to educate them as to the value of ICCCP and encourage participation and membership. However, as it would appear that there is no reliable directory of parent groups, she has run into several challenges relating to the location of groups across the continent. As such she is in the process of identifying methods to reach these groups.

Along with her colleague in Ottawa, the National Coalition of Children's Cancer Agencies was created. Val hopes that this Canadian project will also serve as a vehicle to identify groups that will further the work of ICCCP.

Parent Helping Parents Fund

The Parents Helping Parents Fund (PHPF) remains of great importance to support delegates from low income countries to attend the ICCCP meetings. Through the PPHF member organisations turn ICCCP's vision "We care, We share" into reality. We are extremely grateful to all those members who made a donation to this fund.

Secretariat

The Vereniging Ouders, Kinderen en Kanker (VOKK), the childhood cancer parent organisation in The Netherlands, generously continued the work of the Secretariat for its ninth year. Patty Brouwer and Marianne Naafs-Wilstra are in charge.

Collaboration Programmes

UICC - My Child Matters

Launched jointly by the International Union Against Cancer and Sanofi-aventis in 2005, the My Child Matters campaign is one of the largest initiatives involved in fighting childhood cancer in low and middle income countries. Up to now 39 projects have been launched in 26 countries. Some projects are working together with ICCCP members. However, the huge inequalities in treatment available in developing countries for children with cancer is still a chasm that needs to be bridged. We hope this project will continue to receive funding.

Executive Committee member Kenneth Dollman was invited onto the My Child Matters steering committee in early 2009.

World Child Cancer

As a charity World Child Cancer is now fully operational with four projects delivering. Two new projects, hopefully,

will be given the go ahead before the end of this year. The accounts display World Child Cancer in a very positive light. World Child Cancer has recruited several medical ambassadors and is planning to also recruit parent ambassadors to support its fundraising efforts. An increasing number of valuable volunteers are putting in their time supporting the charity. The board of Trustees is made up by Gordon Morrison, Tom Eden, Maarten Egeler, Terry Hunt, Simon Lala (ICCCPO), Marianne Naafs-Wilstra (ICCCPO), Benson Pau (ICCCPO), Sally Ramsay, Raul Ribeiro and Anu Vedi. World Child Cancer employees are a small team of two people to manage projects and raise essential funds.



World Child Cancer
No child should suffer

For the most up to date information please refer to World Child Cancer's newly developed website at www.worldchildcancer.org.

Statement of Income, Expenditure & Fund Balance As at 31 December 2009

	2009 (EUR)	2008 (EUR)
INCOME		
Membership Fees	32,300.86	24,672.68
Sponsorship	6,150.00	19,760.00
PHPF	10,399.94	15,902.54
Donations	5,237.50	158.31
Childhope Income	8,000.00	9,500.00
EPOC Grant	12,083.33	--
Interest	1,218.44	4,503.08
Total Income	75,390.07	74,496.61
EXPENDITURE		
Executive Meeting Costs	8,627.56	9,147.27
Audit Fees	600.00	500.00
A.G.A. Scholarships	9,683.00	15,100.00
A.G.A. Meeting Expenses	5,759.85	14,151.03
Regional Meetings	13,058.00	11,801.99
Bank Charges	1,036.23	790.77
General Expenses	319.55	1,105.47
Advocacy & Lobbying	1,359.15	800.00
Anniversary Book	3,800.00	--
Secretariat Expenses	5,844.00	5,000.00
Childhope Expenses	16,244.45	9,791.87
EPOC Expenses	813.56	--
Total Expenditure	67,145.35	68,188.40
Net Surplus for the year	8,244.72	6,308.21
Transfer from(to) Childhope Reserve	8,244.45	291.87
Transfer from(to) Conference Reserve	7,500.00	(7,500.00)
Transfer from(to) EPOC Reserve	(11,269.77)	--
Net Surplus(Deficit) after reserve transfer	12,719.40	(899.92)
Fund Balance, Beginning of year	93,842.60	94,742.52
Fund Balance, End of year	106,562.00	93,842.60
Childhope Reserve	1,572.85	9,817.30
Conference Reserve	--	7,500.00
EPOC Reserve	11,269.77	--
Total Organisation Funds	119,404.62	111,159.90

*Subject to audit

Executive Committee

Benson Pau	Chairman, HK SAR, China
Anders Wollmén	Vice Chairman, Sweden
Kenneth Dollman	Secretary, South Africa
Simon Lala	Treasurer, New Zealand
Anita Kienesberger	Member, Austria
Edith Grynszpancholk	Member, Argentina
Ira Soelistyo	Member, Indonesia
Irina Cepinac Ban	Member, Serbia
Val Figliuzzi	Member, Canada

Honorary Members

Christine McIver	Canada
Geoff Thaxter (deceased)	United Kingdom
Gerlind Bode	Germany
Jesús Maria Gonzalez Marin	Spain
Marianne Naafs-Wilstra	The Netherlands
Sadie Cutland	South Africa
Tim Eden	United Kingdom

Secretariat

Marianne Naafs-Wilstra & Patty Brouwer

Email: icccpo-secretariat@vokk.nl

Website: www.icccpo.org

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Members

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 Tasmania	AUSTRALIA	www.cancertas.org.au
Childhood Cancer Support Inc.	AUSTRALIA	www.clcs.org.au
Cure Our Kids Incorporated	AUSTRALIA	www.cureourkids.com.au
Österreichische Kinder-Krebs-Hilfe	AUSTRIA	www.kinderkrebshilfe.at
Charter of "Fighting Leukemia" public union	AZERBAIJAN	mehriban63@mail.ru
ASHIC Foundation	BANGLADESH	www.ashic.org
Children Leukaemia Assistance & Support Services (CLASS)	BANGLADESH	www.classbd.org
Fundación AFANIC	BOLIVIA	www.fundacionafanic.com
The Heart for Kids with Cancer in FBiH	BOSNIA HERZEGOVINA	www.scezadjecu.ba
Núcleo de Apoio à Criança com Câncer (NACC)	BRAZIL	www.nacc.org.br
Caio Roberts Society (GAP)	BRAZIL	joroberts@uol.com.br
Casa de Apoio a Criança com Câncer São Vicente de Paulo	BRAZIL	www.casaapoioocancer.org.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 (KCCFA)	CANADA	www.kidscancercare.ab.ca
Candlelighters Childhood Cancer Support Programs	CANADA	www.candlelighters.net
Kids with Cancer Society	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
OPNICER	COLOMBIA	www.opnicer.org
Fondacion Paola Andrea Velasquez Vivas	COLOMBIA	joisdre@yahoo.com
Colombian Leukemia and Lymphoma Foundation (FCL)	COLOMBIA	www.funcolombianadeleucemiaylinfoma.org
Sanus	CROATIA	www.sanus.hr
Zajedno	CROATIA	doria.verbic@ri.htnet.hr
Firefly	CROATIA	www.krjjesnica.hr
Grupo de Apoyo de Padres de Niños Oncológicos "El Principito"	CUBA	calderon@infomed.sld.cu
Sdružŕí 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
ASONIC	ECUADOR	soveagro@easynet.net.ec
Fundacion Esperanza de Vida	ECUADOR	www.esperanzadevida.com
Sol e Vida	ECUADOR	www.solyvida.info
Jóvenes Contra El Cáncer Fundación	ECUADOR	www.jovenescontraelcancer.org
Alexandria Group of Childhood Cancer Care (AGCCC)	EGYPT	ysaadeldin@gmail.com
ASAPAC	EL SALVADOR	cdemoreno@gmail.com
Mathiwos Wondu - YeEthiopia Cancer Society (MWECS)	ETHIOPIA	www.mathycancersoc.org
SYLVA	FINLAND	www.sylva.fi
L'ENVOL	FRANCE	www.lenvol.asso.fr
UNAPECLE	FRANCE	unionparents@aol.com
Deutsche Leukämie-Forschungshilfe (DLFH)	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@otenet.gr
Fundación Ayúdame a Vivir	GUATEMALA	www.ayuvi.org.gt
Európai Támogatási Egyesület a Rákos Gyermekékért	HUNGARY	www.euroonko.de
Styrktarfelag Krabbameinssjúkra Barna	ICELAND	www.skb.is
Sahayta Charitable Welfare Society	INDIA	www.sahayta.org
Cankids....kidscan	INDIA	www.cankidsindia.org
Cancer Patients Aid Association (CPAA)	INDIA	www.cpaaindia.org
Yayasan Onkologi Anak Indonesia (YOAI)	INDONESIA	www.yoai-foundation.org
The Indonesian Care for Cancer Kids Foundation (YKAKI)	INDONESIA	www.ykaki.org
Care for Children with Cancer Foundation (Yayasan Peduli Anak Kanker) MANADO	INDONESIA	lilikarundeng@yahoo.com
Society To Support Children Suffering From Cancer Known as "MAHAK"	IRAN	www.mahak-charity.org
Barretstown 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 (CMLV)	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
The Tyler Foundation	JAPAN	www.tylershineon.org
Hope for Cancer Kids (HCK)	KENYA	www.hope4cancerkids.org
Association CHANCE - Children Against Cancer	LEBANON	www.chancelebanon.org
Children's Cancer Center of Lebanon (CCCL)	LEBANON	www.cccl.org.lb
Kids First Association	LEBANON	kids_first@live.com
Paguoda	LITHUANIA	www.paguoda.org
Een Häerz fir kriibskrank Kanner asbl	LUXEMBURG	www.kriibskrankanner.lu

Members

	Country	Website or Email
Peperutka	MACEDONIA	www.peperutka.org.mk
Children's Cancer Club	MALAWI	emolyneux@malawi.net
Sarawak Children's Cancer Society (SCCS)	MALAYSIA	www.sccs.org.my
Asociacion Mexicana de Ayuda a Ninos con Cancer, I.A.P. (AMANC)	MEXICO	www.amanc.org
Centro de Apoyo a Niños con Cáncer AC (CANICA)	MEXICO	www.casacanica.org
Association l'Avenir	MOROCCO	www.almoustakbal.org
Noujoum	MOROCCO	www.noujoum.org
Cancer Society Nepal	NEPAL	www.cancersocietynepal.org.np
Vereniging Ouders, Kinderen en Kanker (VOKK)	NETHERLANDS	www.vokk.nl
Child Cancer Foundation	NEW ZEALAND	www.childcancer.org.nz
Asociacion de Padres de Ninos Con Leucemia y Cancer	NICARAGUA	drcardenas@yahoo.com
Children Living with Cancer Foundation (CLCWF)	NIGERIA	www.clwcf.org
Stotteforeningen for Kreftsyke Barn (SKB)	NORWAY	www.kreftsyke-barn.no
Cured Cancer Patients Society (CCPS)	PAKISTAN	www.ccpsociety.com
MITAI - Asociación de Padres para ayuda a niños con cancer	PARAGUAY	mitai@conexion.com.py
Asociación de Padres de Niños con Cáncer de la Comunidad Valenciana (ASPANION)	PERU	www.aspanion.org
Esperantra (Asociacion de Ayuda al Paciente con Cancer)	PERU	www.esperantra.org
Cancer Warriors Foundation Inc	PHILIPPINES	www.c-warriors.org
Acreditar	PORTUGAL	www.acreditar.org.pt
Association for Services for Communities Voluntaris of Portuguese-Speaking Countries	PORTUGAL	www.asv-cplp.com
Association P.A.V.E.L.	ROMANIA	www.asociatiapavel.home.ro
The Holiday of Life Charity fund	RUSSIA	www.holilife.ru/blago
Nadejda	RUSSIA	www.oo-nadejda.com
Children & Parents Against Cancer (CAPAC)	RUSSIA	www.capac.ru
Triendinstvo	RUSSIA	www.triendinstvo.edu.severodvinsk.ru
ISKORKA, "Sparkle"	RUSSIA	kezy-girl@mail.ru
Regional Charity Organisation for helping Children in behalf of St. Elizabeth	RUSSIA	tony_m02@mail.ru
Social Charitable Foundation for Help to Children suffered from leukemia	RUSSIA	www.angela-vavilova.ru
ASEAC	SENEGAL	seynabila@yahoo.fr
Nacionalno Udruženje Roditelja Dece Obolele od Raka (NURDOR)	SERBIA	www.nurdor.org.rs
Children's Cancer Foundation (CCF)	SINGAPORE	www.ccf.org.sg
Slovanian childhood cancer parent organisation (SloDSR)	SLOVENIA	slodsr@gmail.com
Childhood Cancer Foundation South Africa (CHOC)	SOUTH AFRICA	www.choc.org.za
Korean Association for Children with Leukemia and Cancer (KACLCL)	SOUTH KOREA	www.soam.or.kr
Federación Española de Padres de Niños con Cáncer (FEPNC)	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 Mellansverige	SWEDEN	www.barncancerfonden.se/Mellansverige
Barncancerföreningen Östra Götland	SWEDEN	www.barncancerforeningen.se/ostra
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@gmail.com
The Just Because Foundation	TRINIDAD & TOBAGO	justbecause@mail.tt
LÖSEV	TURKEY	www.losev.org.tr
Parents & Friends of Children with Cancer Simferopol, Ukraina	UKRAINE	http://donor.org.ua
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 National Charitable Fund "Zaporuka" ("Guarantee")	UKRAINE	www.zaporuka.com.ua
National Alliance of Childhood Cancer Parents Organisations (NACCPO)	UNITED KINGDOM	www.naccpo.org.uk
Children's Cancer And Leukaemia Group (CCLG)	UNITED KINGDOM	www.cclg.org.uk
CLIC Sargent	UNITED KINGDOM	www.clicsargent.org.uk
Wilms at Home	UNITED KINGDOM	www.wilmsathome.org.uk
American Childhood Cancer Organisation	USA	www.americanchildhoodcancer.org
Asociacion Venezolana de Padres de Ninos con Cancer (ASOVEPANICA)	VENEZUELA	asovepanica@cantv.net
Childhood Cancer Family Group in Central Vietnam (CCFGCV)	VIETNAM	http://ccfgvietnam.googlepages.com
Childrens Cancer Relief	ZIMBABWE	info@kidzcan.co.zw

* 132 member organisations in 78 countries