### ANNUAL REPORT 2011–122 • WE CARE, WE SHARE THE INTERNATIONAL CONFEDERATION OF CHILDHOOD CANCER PARENT ORGANIZATIONS



## Objectives

# Mission

#### MESSAGE FROM THE CHAIR

The impact that ICCCPO has made, through the activities of our members, to improve conditions for those affected by and caring for childhood cancer, has grown significantly this past year. However, we cannot become complacent as there is still much to be done in many countries before we can announce that all children are receiving effective care.

This past year was unique in that a set of global voluntary targets for the prevention and control of Non-Communicable Diseases (NCDs) is being debated at the highest level. Although children with NCDs are not specifically mentioned, ICCCPO continues to try to influence decisions taken. To this end not only did ICCCPO, with input from the WHO, Carmen Auste, Kenneth Dollman, Edith Grynszpancholc and Benson Pau, prepare a leaflet for distribution to those attending the World Health Assembly meeting in Geneva in April, but board members, Benson Pau and Edith Grynszpancholc also attended a number of meetings with strategic partners in various parts of the world throughout the year.

It was also the first time that ICCCPO held regional meetings in so many regions in one year – meetings were held in Africa, Asia, Europe, Balkan countries, and Latin America.

In April the chairs of SIOP and ICCCPO met in Geneva to discuss future collaboration. During this meeting it was agreed that for the first time members of SIOP throughout the world would join forces with members of ICCCPO to celebrate International Childhood Cancer Day. During the same trip Benson Pau and Kenneth Dollman visited the WHO to discuss areas of co-operation regarding a WHO/ICCCPO project.

I wish to thank, among others: each and every member of ICCCPO for working so tirelessly to bring about improvements to the care that is offered, and available, to children and their families with cancer; SIOP, UICC, WHO for our close working relationship; the Paediatric Oncology in Developing Countries (PODC) through its working groups, which include members of the board and ICCCPO, for the ground-breaking work they do to improve cancer care in developing countries; and last but not least all board members who work together so well as a team and never give up on our mission to share information and experiences in order to improve access to the best possible treatment and care for children with cancer everywhere in the world.

Sincerely

Kenneth Dollman Chairman

#### **ANNUAL CONFERENCE**

The 43rd annual conference of ICCCPO was held in Auckland, New Zealand in October 2011. Attended by 60 parent group representatives, delegates came together to seek support and knowledge from their peers from around the world. The survivor group (ICCSN) has become an important part of the conference as we recognize the unique needs of those who have survived childhood cancer. The 2011 ICCCPO conference program offered support through 30 presentations that informed on the psychosocial and medical needs of the patient and their families.

#### **ANNUAL GENERAL ASSEMBLY & MEMBERSHIP**

The General Assembly accepted 10 new members - 4 full and 6 associate - from Australia, Canada, Croatia, India, Italy, Luxembourg, Palestine and Serbia. This brought our membership to 148 member organisations from 81 countries. The General Assembly elected Anders Wollmén from Sweden as member of the Executive Committee, and re-elected Anita Kienesberger from Austria and Kenneth Dollman from South Africa. Kenneth Dollman was elected Chair and Benson Pau Vice-Chair.

#### EXECUTIVE COMMITTEE MEETINGS

The first of two meetings was held in Auckland just prior to the Annual Conference and the second in London, where Clic-Sargent generously allowed the board the use of a boardroom.

#### **CONTINENTAL/REGIONAL MEETINGS & ACTIVITIES**

#### Africa

The 2012 ICCCPO Africa regional meeting was held in March in Cape Town, South Africa in combination with SIOP Africa and the local parent group, CHOC's, biannual conference. The meeting was attended by 85 delegates from 12 countries. An African Workshop was organised that focused on developing capacity through the sharing of experiences of delegates and the expertise of those who presented. The rest of the programme focused on experts sharing projects and programmes that improve the psycho-social care of children and their families. Board member Kenneth Dollman paid a site visit to groups in Namibia, Mozambique and Cameroon. New childhood cancer foundations were formed in Tanzania, Cameroon and most recently Zambia. ICCCPO members and member groups are involved in supporting projects sponsored by World Child Cancer in Ghana, Cameroon, Mozambigue and Malawi.

#### Asia

The 2012 Asia Regional Meeting "Give Hope to Children with Cancer" was held in April in Yogyakarta, Indonesia, organised by Ira Soelistyo and her team. The meeting was attended by 190 participants, from 13 countries. It provided an opportunity for networking and building and strengthening alliances between parent groups and medical practitioners. For the first time this meeting included a separate programme for survivors and a declaration prepared by survivors themselves, named "Our Voice, Strength and Well-being".

In September, Kazuyo Watanabe, from Asian Children's Care League, (ACCL-Japan) visited families of children with cancer and health practitioners in Nepal. In December, Kazuyo, who has been collaborating with the medical team and parents in Hue for some years now, together with board members Carmen Auste and Benson Pau visited Hue, Vietnam, to develop the growth of the parent group there.

#### Latin America

The 2012 Regional Meeting of countries in Latin America was held in September in Colombia, where 11 countries were represented. Highlights included: an interview on CNN in Spanish which afforded the opportunity of sharing the inequalities in access to treatment among countries within Latin America; the presentations on advocacy and awareness; and the presentation by local representatives from the Government and Health Care Services explaining how they are collaborating with childhood cancer foundations in Colombia. Many countries in the region are improving access to treatment for children with cancer through new legislation. Since the last SLAOP Meeting in Bolivia ICCCPO members in different cities are working together to organise local meetings.

Board member Edith Grynzspancholc paid site visits to México and Colombia. In México together with ICCCPO member, AMANC, a project is underway to legislate improved access to medical treatment for children with cancer. In Colombia, ICCCPO is involved with mentorship of the World Child Cancer project to facilitate the future sustainability of the project.

#### Europe

The 3rd European ICCCPO Regional Meeting held in April 2012 in Schengen/Luxembourg, was attended by delegates from 16 different countries. The focus of this meeting was the different EU-projects in which ICCCPO is an active partner (ENCCA, IntReALL, EPOC and PanCareSurFup). Ideas for ICCD, the progress of the Survivorship Passport, a report on home care, an update on the Central Paediatric Oncology Centre in the Netherlands and ethical questions in connection with consent giving for bio-banking were discussed. A close relationship with SIOP-Europe and World Child Cancer was stressed.

In collaboration with SIOP-Europe, European members of parliament were addressed to inform them of the importance of early detection of childhood cancer, specifically brain tumours, and the revision of the EU Clinical Trials Directive, which is up for discussion in the EU Parliament. In October 2011, at the European Standards of Care follow up conference (in Warsaw, Poland), a document, which agrees on the requirements for paediatric oncology centres in Europe, was translated into seven different languages.

An important milestone was the founding of a Parent and Patient Advocacy Committee (PPAC), consisting of parents and survivors, which will convene regularly to discuss and decide on ethical and practical issues related to regulations and demands for Paediatric Oncology within Europe.

The 6th regional ICCCPO meeting of countries from the Balkan region was held in Belgrade, Serbia on 28 April, 2012. It was hosted by "Zvončica" and supported by ICCCPO. There were 87 participants from 6 countries, among them parents, survivors, doctors, psychologists, social workers, play-therapists and representatives from the local government authority. Presentations included those on: parents' involvement in professional medical projects and research; parents as advocates; parents as the protagonists for best possible treatment; and the importance of parents' participation in information dissemination.

#### **North America**

Successful liaison with established childhood cancer foundations across Canada continues, but the need to create groups where none exist in areas across the country requires further attention.

The recent serious shortage of production of preservative-free methotrexate experienced in the USA was resolved through interventions by ICCCPO member, the American Childhood Cancer Organization (ACCO), and other cancer organisations with which they collaborated. It was through a grassroots initiative of childhood cancer families to speak out on the impact of this shortage and to demand solutions that the FDA accelerated approval for an additional company to start production of this drug. Increased supply of the drug has alleviated immediate shortages.

#### Oceania

Visits were made to Sydney and Melbourne where there are many parent groups serving the specific needs of children with cancer and their families. More work still needs to be done on convincing the groups of the value of joining ICCCPO and the contributions they can make.

The Pacific Child Cancer project has started its first year with the medical team visiting Fiji, Samoa and Tonga. One of the goals of the project is the formation of parent groups in the Pacific Islands. Whilst the Tonga Child Cancer Foundation has now become a fully functional parent support group, work is continuing on establishing similar groups in Fiji and Samoa.

#### **COMMUNICATION & INFORMATION**

#### **Donations and Sponsorship**

ICCCPO has received donations from a number of sources to help with its work. Seven member organisations contributed to the Parents Helping Parents Fund that supports representatives from organisations in low income countries to attend the annual ICCCPO conference. One organisation made a donation specifically for ICCCPO regional work. Should you be able to and wish to support ICCCPO work, please contact the secretariat.

#### Secretariat

ICCCPO once again wishes to thank the parent organisation VOKK in The Netherlands for their generosity and support by hosting the Secretariat for the eleventh consecutive year. Marianne Naafs-Wilstra heads the secretariat, assisted by Patty Brouwer who fulfills the role of part-time assistant. ICCCPO is grateful for all that is done to keep members updated on the activities of the board, ICCCPO and other related organisations.

#### Newsletter, website and social media

Social media has become an important communication tool and supplements the ICCCPO website and newsletters.

Between April 17 and December 31 the new ICCCPO website had 5393 visitors, of which 65% were first-time visitors. There were 30530 page-views.

During the course of the year a Twitter account (@IntChildCancer) was setup and as of 31 December 2011, has 178 followers.

The electronic ICCCPO newsletter is sent out monthly, reporting news from the board and from different member organisations. It serves as a link between members and the interested public as anyone can sign up via www.icccpo.org.

#### UNAUDITED STATEMENT OF FINANCIAL POSITION AS AT 31 DECEMBER 2011

	2011 EUR	2010 EUR
INCOME Membership Fees Sponsorship PHPF Donations Childhope Income Sundry Income EPOC Grant Interest Total Income	27,132 3,204 3,500 7,552 - 3,380 17,309 1,976 <b>64,053</b>	28,371 6,350 10,173 10,494 12,743 1,168 2,490 <b>71,789</b>
iotai meome	04,033	71,709
EXPENDITURE Executive Meeting Costs Audit Fees A.G.A. Scholarships A.G.A. Meeting Expenses Regional Meetings Bank Charges General Expenses Advocacy & Lobbying Secretariat Expenses Childhope Expenses EPOC Expenses <b>Total Expenditure</b>	12,928 600 3,500 699 5,435 437 3,437 6,000 0 4,737 <b>37,810</b>	12,013 600 4,700 3,295 13,220 1,021 58 1,328 6,182 14,316 1,317 <b>58,050</b>
NET SURPLUS FOR YEAR Transfer from (to) Childhope Reserve Transfer from(to) Conference Reserve Transfer from (to) EPOC Reserve Transfer from (to) Regional Reserve NET SURPLUS(DEFICIT) AFTER TRANSFERS	26,243 - (12,573) (5,000) 8,671	13,739 1,573 (11,000) 1,316 (3,534) 2,094
Fund Balance, Beginning of year Fund Balance, End of year	108,656 117,326	106,561 108,655
Conference Reserve EPOC Reserve Regional Outreach Reserve ORGANIZATION FUNDS	11,000 22,526 8,534 159,385	11,000 9,953 3,435 133,143

#### **COLLABORATION PROGRAMMES**

#### **International Childhood Cancer Day**

This year for the first time many ICCCPO members were joined by SIOP members on 15 February where they distributed cards with the early warning signs of childhood cancer. In many countries a campaign was organised during the whole of February where a variety of awareness events were held.

#### **ICCSN**

Sabine Karner and Michaela Willi, ICCSN representatives, organised the programme for survivors during the Annual congress in New Zealand. The sessions for survivor groups included a film presentation, reports of both national and cross border survivor group activities and mentoring projects.

#### **World Child Cancer**

World Child Cancer, a subsidiary of ICCCPO, funds projects that help children with cancer in low and middle income countries. It funds medical twinning partnerships by linking hospitals in developed with those in developing countries. Trustees of World Child Cancer have always recognized the importance of good psycho-social support of families, however this year they have gone one step further and agreed that where possible, new projects should also include funding for psycho-social support. Benson Pau, Marianne Naafs-Wilstra, Simon Lala and Kenneth Dollman (World Child Cancer trustees) provide valuable advice and input where this is concerned. The charity has once again increased the amount of children it helps in the 8 projects supported in Bangladesh, Cameroon, Colombia, Ghana, Malawi, Mozambique, Pacific Islands and Philippines. Projects are in development with AHOPCA, Namibia and Zambia for next year. The charity has benefitted from the generous support of ICCCPO members.

#### **My Child Matters**

2010

As a partnership between the Sanofi Espour Foundation and the UICC, this initiative continues to fund a number of projects associated with childhood cancer in developing countries. Many of these projects are driven by or work together with members of ICCCPO. It is through the generous donation of the Sanofi Espour Foundation that these projects are making a difference in lives of children with cancer.

Executive Committee member Kenneth Dollman continues to serve on the My Child Matters steering committee.

#### **UICC - ICCCPO Vietnam Project**

Since 2010, UICC has been supporting Hue Central Hospital, Vietnam, with the focus on enhancing pediatric oncology care and increasing support for childhood cancer patients. In March 2012, ICCCPO, with funding support from UICC and with ACCL as implementing partner, embarked on a project for organisational development and strengthening of the Hue Central Hospital parent group.

#### Non-Communicable Diseases (NCD) Advocacy

ICCCPO continued to drive the advocacy of childhood cancer within the context of the UN NCD. In September, 2011, ICCCPO representatives attended the UN NCD High-Level Meeting in New York. They also hosted a round table discussion to broaden alliances for childhood cancer. In March, 2012, ICCCPO collaborated in the first international NCD Child conference "A Roadmap Beyond the UN Summit on NCDs". The forum led to the establishment of a multi-stakeholder movement for NCD CHILD and the issuance of the Oakland Statement "Putting Children and Adolescents in the Global NCD Agenda".

#### **Building a Partnership with WHO**

In March, 2012, Kenneth Dollman and Benson Pau met with Dr Oleg Chestnov, the Assistant Director-General (NCD's and Mental Health), and other key WHO officials. Three areas for co-operation were agreed, namely: increasing awareness for early diagnosis of childhood cancers, making childhood cancer medicines available and accessible, and improving pain care management for children with cancer. This resulted in the development of an unprecedented joint ICCCPO-WHO leaflet which was distributed, with support from WHO, during the 65th Annual WHA meeting held in Geneva in May 2012.

#### **MEMBERS**

COUNTRY/REGION WEBSITE OR EMAIL ARGENTINA

ARGENTINA

AUSTRALIA

AUSTRALIA

AUSTRALIA

AUSTRALIA

AZERBAIJAN

BANGLADESH

BANGLADESH

AUSTRIA

BOLIVIA

BRAZIL

BRAZIL

BRAZIL

CANADA

CANADA

CANADA

CANADA

CANADA

CANADA

COLOMBIA

COLOMBIA CROATIA CROATIA

CROATIA

CROATIA

DENMARK

DENMARK

ECUADOR

ECUADOR

ETHIOPIA

FINLAND

FRANCE

FRANCE

GHANA

GREECE

GREECE

GUATEMALA

HUNGARY

ICELAND

INDIA

INDIA

INDIA

INDIA

INDIA

IRAN

IRAQ

IRELAND

IRELAND

ISRAEL

ITALY

ITALY

ITALY

ITALY

ITALY

JAPAN

JAPAN

JAPAN

KENYA

KENYA

LEBANON

LEBANON

LEBANON

LITHUANIA

LUXEMBURG

MACEDONIA

MALAWI

MALAYSIA

INDONESIA

INDONESIA

INDONESIA

GERMANY

EL SALVADOR

EGYPT

CHILE

CHINA

ARMENIA

Fundación Mateo Esquivo Fundación Natalí Dafne Flexer Society to Help Children with Cancer Cancer Council Tasmania Childhood Cancer Support Inc. Children's Cancer Centres Parent Advisory Group (CCCPAG) Cure Our Kids Incorporated Österreichische Kinder-Krebs-Hilfe Charter of "Fighting Leukemia' ASHIC Foundation 'Children Leukemia Assistance & Support Services (CLASS)" Fundación AFANIC The Heart for the Kids with Cancer in FBiH Caio Roberts Society (GAP) Casa de Apoio a Criança com Câncer São Vicente de Paulo Núcleo de Apoio à Crianca com Câncer (NACC) British Columbia Childhood Cancer Parents Association Candlelighters Childhood Cancer Support Programs Childhood Cancer Canada Foundation Kids Cancer Care Foundation of Alberta (KCCFA) Kids with Cancer Society Ontario Parents Advocating for Children with Cancer (OPACC) Fundación Nuestros Hijos Guangzhou Gold-ribbon Children Parents Center Little Life Warrior Society Pau Kwong Wun Charitable Foundation Colombian Leukemia and Lymphoma Foundation (FCL) OPNICER Firefly Ljubav na Djelu Sanus Zajedno Sdružení Šance Børnecancerfonden Familier med kræftramte børn (FMKB) Fundación Amigos Contra el Cáncer Infantil, Inc. (FACCI) Jóvenes Contra el Cáncer Fundación Sol y Vida Fundación Alexandria Group of Childhood Cancer Care (AGCCC) ASAPAC Mathiwos Wondu - YeEthiopia Cancer Society (MWECS) **SYLVA** L'ENVOL pour les enfants européens Union Nationale des Associations de Parents d'Enfants atteints de Cancer ou Leucémie (UNAPECLE) Deutsche Leukämie-Forschungshilfe (DLFH) Ghana Parents Association for Childhood Cancers (GHAPACC) Floga - Parents Association of Children with Cancer IASO Fundación Ayúdame a Vivir Európai Támogatási Egyesület a Rákos Gyermekekért Styrktarfélag Krabbameinssjúkra Barna Cancer Patients Aid Association (CPAA) Cankids....kidscan Nivethan Sahayta Charitable Welfare Society St. Jude India ChildCare Centres Indonesian Care for Cancer Kids Foundation (YKAKI) Indonesian Childhood Cancer Foundation (YOAI) Indonesian Care for Childhood Cancer Foundation Society to Support Children Suffering from Cancer (MAHAK) The Cancer Children Organization Barretstown Camp CanTeen Ireland Havim Association Associazione Bianca Garavaglia Comitato Maria Letizia Verga (CMLV) Federazione Italiana Associazioni Genitori Oncoematologia Pediatrica (FIAGOP) Fondazione Cure2Children Soleterre strategie di pace ONLUS Asian Children's Care League (ACCL) Children's Cancer Association of Japan (CCAJ) The Tyler Foundation Childhood Cancer Initiative Hope for Cancer Kids Foundation (HCK) CHANCE Association Children's Cancer Center of Lebanon (CCCL) Kids First Association Paguoda Fondatioun Kriibskrank Kanner Een Häerz fir kriibskrank Kanner asbl Peperutka Children's Cancer Club

Sarawak Children's Cancer Society (SCCS)

www.fme.org.ar www.fundacionflexer.org badalyan@doctor.com www.cancertas.org.au www.ccs.org.au/ www.rch.org.au/ccc www.cureourkids.com.au www.kinderkrebshilfe.at mehriban63@mail.ru www.ashic.org www.facebook.com/classbd www.fundacionafanic.com BOSNIA HERCEGOVINA www.srcezadjecu.ba iroberts@uol.com.br www.casaapoiocancer.org.br www.nacc.org.br www.bcccpa.org www.candlelighters.net www.childhoodcancer.ca www.kidscancercare.ab.ca www.kidswithcancer.ca www.opacc.org www.fnh.cl www.jiazhanghui.org.cn HKSAR, CHINA HKSAR, CHINA www.hkllws.org/en\_index.php www.pkwfoundation.org www.funcolombianadeleucemiaylinfoma.org www.opnicer.org www.krijesnica.hr www.ljubavnadjelu.hr www.sanus.hr doria.verbic@ri.htnet.hr CZECH REPUBLIC www.sancecz.org www.boernecancerfonden.dk www.fmkb.dk DOMINICAN REPUBLIC www.facci.org.do www.jovenescontraelcancer.org www.solyvida.info ysaadeldin@gmail.com www.facebook.com/ASAPACSV www.mathycancersoc.org www.sylva.fi www.lenvol.asso.fr unapecle.medicalistes.org www.kinderkrebsstiftung.de www.ghapacc.org www.floga.org.gr iaso@otenet.gr www.ayuvi.org.gt www.euroonko.de www.skb.is www.cpaaindia.org www.cankidsindia.org www.nivethan.org www.sahayta.org www.stjudechild.org www.ykaki.org www.yoaifoundation.org lilikarundeng@yahoo.com www.mahak-charity.org iccpo\_iraq@yahoo.com www.barretstown.org www.canteen.ie www.hayim.org.il www.abianca.org www.comitatomarialetiziaverga.it www.fiagop.it www.cure2children.org www.soleterre.org www.accl.jp www.ccaj-found.or.jp www.tylershineon.org omachjoseph@yahoo.com www.hope4cancerkids.org www.chancelebanon.org www.cccl.org.lb petern@inco.com.lb www.paguoda.org LUXEMBOURG www.fondatioun.lu www.kriibskrankkanner.lu www.peperutka.org.mk emolyneux@malawi.net www.sccs.org.my

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Asociacion Mexicana de Ayuda a Ninos con Cancer, I.A.P. (AMANC)	MEXICO	www.amanc.org
Centro de Apoyo a Ninos con Cancer CANICA A.C.	MEXICO	www.casacanica.org
Avenir Association	MOROCCO	association.lavenir@gmail.com
Noujoum	MOROCCO	www.noujoum.org
ASSOCIAÇÃO SORRISO DA CRIANÇA	MOZAMBIQUE	www.sorrisodacrianca.co.nr
Cancer Council Nepal (CCN)	NEPAL	cancercouncilnepal.org.np
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 (CLWCF)	NIGERIA	www.clwcf.org
Stotteforeningen for Kreftsyke Barn (SKB)	NORWAY	www.kreftsyke-barn.no www.thetigerteam.org
Cured Cancer Patients Society (CCPS) Foundation Smile of Hope (SOH)	PAKISTAN PALESTINE	www.smileofhope.org
MITA'I - Asociacón de Padres para ayuda a niños con cancer	PARAGUAY	www.mitai.org.py
Asociación de padres de niños con cáncer (ASPANION)	PERU	www.aspanion.es
Esperantra (Asociacion de Ayuda al Paciente con Cancer)	PERU	www.esperantra.org
Cancer Warriors Foundation, Inc	PHILIPPINES	www.c-warriors.org
Kythe Inc	PHILIPPINES	www.kythe.org
Acreditar	PORTUGAL	www.acreditar.org.pt
Association for Services for Communities Voluntaris of	PORTUGAL	www.asv-cplp.com
Portuguese-Speaking Countries		
Association P.A.V.E.L.	ROMANIA	www.asociatiapavel.ro
Children and Parents Against Cancer (CAPAC)	RUSSIA	www.capac.ru
ISKORKA, "Sparkle"	RUSSIA	kezy-girl@mail.ru
Nadejda	RUSSIA	www.oo-nadejda.com
Regional Charity Organization for helping Children in behalf of	RUSSIA	www.saint-elizabeth.ru
St. Elizabeth		
Social Charitable Foundation for Help to Children suffered	RUSSIA	www.angela-vavilova.ru
from leukemia		
The Holiday of Life Charity Fund	RUSSIA	www.holilife.ru/blago
Trindinstvo	RUSSIA	www.triedinstvo.edu.severodvinsk.ru
ASEAC	SENEGAL	seynabila@yahoo.fr
"ZVONČICA" Childhood Cancer Parent Organization "ČIKA BOCA" Childhood Cancer Parent Organization	SERBIA	www.zvoncica.org.rs
Nacionalno Udruženje Roditelja Dece Obolele od Raka (NURDOR)	SERBIA SERBIA	www.cikaboca.org www.nurdor.org.rs
Rowaca Cancer Group - Sierra Leone	SIERRA LEONE	rowacacancersl.webs.com
Children's Cancer Foundation (CCF)	SINGAPORE	www.ccf.org.sg
Slovanian childhood cancer parent organisation (SloDSR)	SLOVENIA	slodsr@gmail.com
CHOC Childhood Cancer Foundation South Africa	SOUTH AFRICA	www.choc.org.za
Korean Association for Children with Leukemia and Cancer (KACLC)	SOUTH KOREA	soaam.or.kr/
Federación Española de Padres de Niños con Cáncer (FEPNC)	SPAIN	www.cancerinfantil.org
Barncancerfonden	SWEDEN	www.barncancerfonden.se
Barncancerföreningen i Stockholmsregionen	SWEDEN	www.barncancerfonden.se/Stockholm
Barncancerföreningen Mellansverige	SWEDEN	www.barncancerfonden.se/Mellansverige
Barncancerföreningen Norra	SWEDEN	www.barncancerfonden.se/Norra
Barncancerföreningen Östra Götaland	SWEDEN	www.barncancerfonden.se/Ostra
Barncancerföreningen Södra	SWEDEN	www.barncancerfonden.se/sodra
Barnecancerföreningen i Västra Sverige	SWEDEN	www.barncancerfonden.se/vastra
Kinderkrebshilfe Schweiz	SWITZERLAND	www.kinderkrebshilfe.ch
BASMA Chlidren with Cancer Support Association	SYRIA	www.basma-syria.org
Child Cancer Foundation of Tonga	TONGA	ccft@gmail.com
The Just Because Foundation	TRINIDAD & TOBAGO	thejustbecausefoundation.com
LÔSEV Bless a Child Foundation	TURKEY UGANDA	www.losev.org.tr www.blessachildfoundation.org
Charitable Fund VIDEN	UKRAINE	viden@sm.ukrtel.net
Childhood Cancer Foundation "Crab"	UKRAINE	www.krab.org.ua
David Deacon Charity Institution	UKRAINE	seelig-david@t-online.de
Mercy Mission "Overcoming", Parents & Friends of Children	UKRAINE	www.donor.org.ua
with Cancer	CARGE INC.	
Ukrainian National Charitable Fund "Zaporuka" ("Guarantee")	UKRAINE	www.zaporuka.com.ua
Childhood Cancer Parents Alliance (CCPA)	UNITED KINGDOM	www.ccpa.org.uk
CLIC Sargent	UNITED KINGDOM	www.clicsargent.org.uk
Wilms at home	UNITED KINGDOM	www.wilmsathome.org.uk
American Childhood Cancer Organization	UNITED STATES	www.acco.org
SuperSibs!	UNITED STATES	www.supersibs.org
Asociacion Venezolana de Padres de Ninos con Cancer (ASOVEPANICA	) VENEZUELA	asovepanica@cantv.net
Childhood Cancer Family Group in the Central Vietnam (CCFGCV)	VIETNAM	ccfgvietnam.googlepages.com/
Childrens Cancer Relief	ZIMBABWE	www.kidzcanzimbabwe.org

#### **EXECUTIVE COMMITTEE**

**Kenneth Dollman** Benson Pau Simon Lala Anders Wollmén Anita Kienesberger Carmen Vallejo Auste Edith Grynszpancholc Irina Cepinac Ban Val Filiuzzi

Chairman, South Africa Vice Chairman, China Treasurer, New Zealand Member, Sweden Member, Austria Member, **Philippines** Member, Argentina Member, Serbia Member, Canada

#### **HONORARY MEMBERS**

Jesús María Gonzalez Marin **Gerlind Bode** Marianne Naafs-Wilstra Sadie Cutland Tim Eden Christine Wandzura Mark Chesler The late Geoff Thaxter

Spain Germany Netherlands South Africa United Kingdom Canada United States of America United Kingdom

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