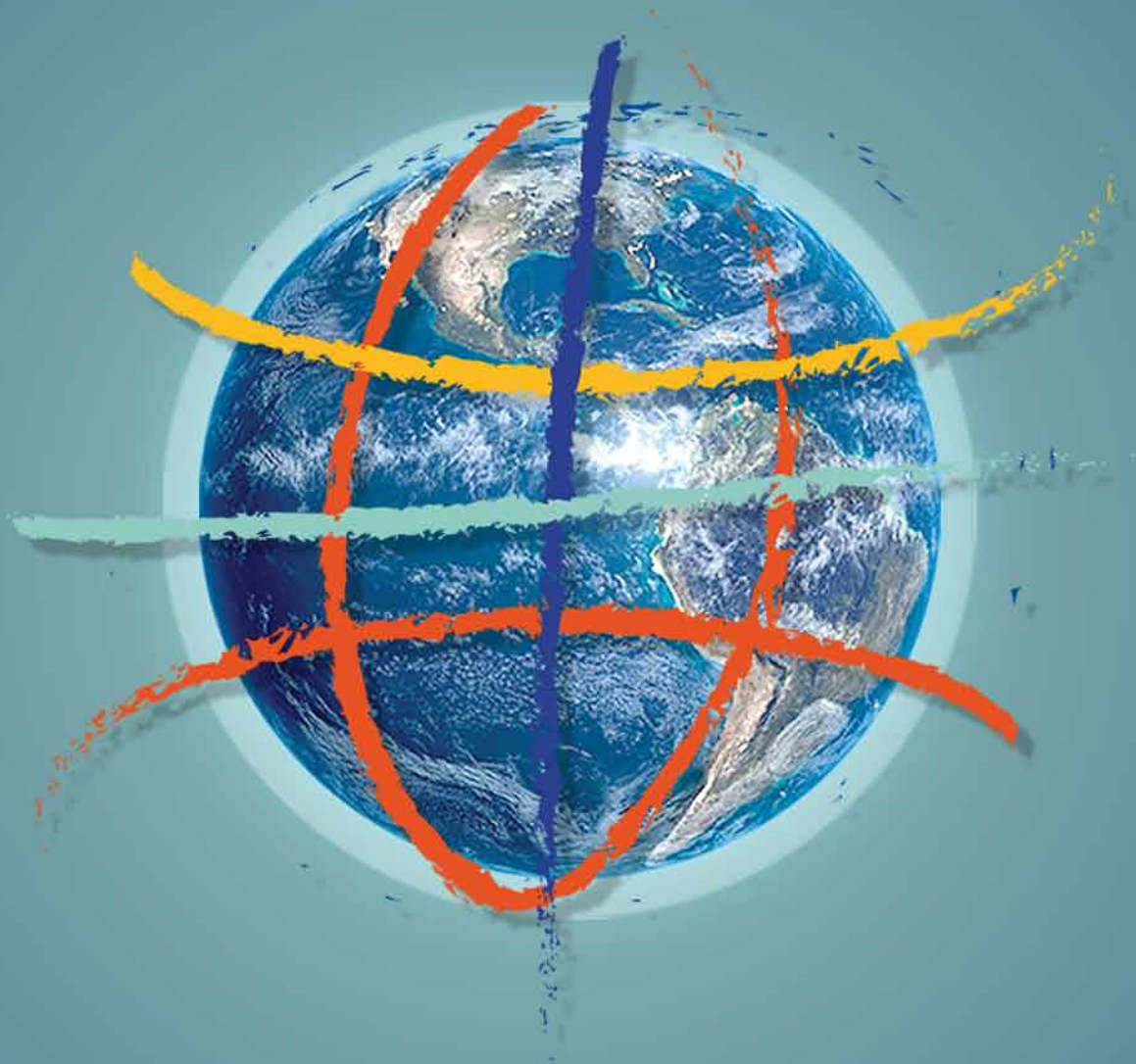


Annual Report 2012-13



WE CARE, WE SHARE
THE INTERNATIONAL CONFEDERATION OF
CHILDHOOD CANCER PARENT ORGANIZATIONS



MESSAGE FROM THE CHAIR

On behalf of the board it is a pleasure to share this report on the progress of ICCCPo over the past year. We have once again experienced an increase in the footprint of childhood cancer support organisations worldwide through the selfless and unfailing efforts individuals put into reaching out to those affected by cancer.

As evidenced below, ICCCPo, our members and their volunteers continue to assist and advise on childhood cancer matters at local, regional and international levels. More ICCCPo members are reaching out to one another and offering funding, mentoring and support to those from the developing world. We are also seeing an ever increasing role played by our survivor organisation the ICCSN and their representatives in matters concerning, and of concern to, survivors.

ICCCPO continues to enjoy closer working relations with SIOP, WHO and the UICC as we continue striving to achieve common goals.

I wish to thank all our members, their staff and the volunteers who assist them for the support they offer daily, often under very difficult political circumstances, to those affected by cancer: the patients, families, doctors, nurses and related medical professionals. In closing, my deepest appreciation to the ICCCPo board members and regional representatives for continuing to work so tirelessly to achieve our goals.

Sincerely



Kenneth Dollman
Chairman

ANNUAL CONFERENCE

The annual conference of ICCCPo was held in London, United Kingdom, in October 2012 in combination with the 44th SIOP annual congress. Attended by over 100 parent group representatives, delegates came to listen to inspiring speakers on topics that shared support and knowledge with their peers from around the world. Once again the survivor group (ICCSN) was an important part of the conference and delegates could learn about the needs and concerns of those who have survived childhood cancer. Our thanks to Abby White and Rachael Olley who represented ICCCPo on the LOC and to the Childhood Cancer Parents Alliance UK (CCPA) for hosting the ICCCPo Meet & Greet and Annual Dinner. Our thanks also go to the ICCCPo conference committee, chaired by Val Figliuzzi, for organising the programme content.

ANNUAL GENERAL ASSEMBLY AND MEMBERSHIP

The General Assembly accepted 15 new members – 9 full and 6 associate – from Bulgaria, Canada, China, Colombia, Costa Rica, India, Indonesia, Morocco, Namibia, Panama, Serbia, Venezuela, and Zambia. Membership of 5 organisations was revoked. This brought our membership to 158 member organisations from 86 countries.

The General Assembly elected Marcela Zubieta from Chile as member of the Executive Committee, and re-elected Benson Pau from China. Val Figliuzzi from Canada and Irina Ban from Serbia stepped down from the Executive Committee after completing their term in office.

EXECUTIVE COMMITTEE MEETINGS

The first of two meetings were held in London just prior to the Annual Conference and the second in Vienna, Austria, where Österreichische Kinder-Krebs-Hilfe generously hosted the board and allowed the board the use of a boardroom.

CONTINENTAL REGIONAL MEETINGS AND ACTIVITIES

Africa

A major focus area continues to be the development of childhood cancer parent/support groups in countries and areas where none exist. This has proved so successful that many newer members are now able to finance some psycho-social services to patients and their families. Kenneth Dollman paid a visit to Ethiopia where a new parent group has been established in addition to the one that exists. New groups formed within the last two years are already creating an improved awareness of childhood cancer in their countries, for example, in Tanzania and Zambia the first homes for parents from out of town have been opened. Almost all members in Africa have started Awareness Campaigns which include the early warning signs of childhood cancer that reach the public, health professionals and now also traditional healers, where five countries now report referrals received directly from traditional healers. In Sierra Leone the member registered a tabloid newspaper with the priority being childhood cancer and public health issues to create a better awareness of childhood cancer.

Many more countries in Africa are starting innovative projects like the mobile palliative service in the Cameroon. Now more than ever countries are benefiting from the co-operation and support of international organisations, donors and medical teaching institutions who are engaging in joint ventures, twinning projects, training and the sharing of knowledge and expertise to develop the capacity of professional staff at treatment units throughout Africa. This has resulted in a number of new childhood cancer wards being opened in Africa.

Latin America

Marcela Zubieta (Chile) and Edith Grynszpanchalc (Argentina) are increasing ICCCPPO membership in the region and organizing activities such as The Rotary Initiative, which was launched in March, 2013.

A number of meetings were organised in Latin America; namely, the 6th Latin American Regional Meeting held in Panamá from 15-18 November 2012 where almost 60 representatives from 32 different organisations and 14 countries attended the meeting; the 7th LATAM Regional Meeting held Santiago, Chile 21-24 August 2013 organised by Fundación Nuestros Hijos and where speakers from national and international organisations shared their experience and knowledge; the National Meeting of childhood cancer foundations (CCFs) organised by Edith Grynszpanchalc in Cochabamba, Bolivia, where the aim was to improve networking and access to treatment through the start-up of a National CCFs' Web Site and the use of special software for the management of patients' needs; a National Volunteers meeting organised by Fundación amigos del niño con leucemia y cancer (FANLYC); the 4th National and 2nd International Meeting of Caretakers, held in Bogotá, was organised by Fundación María José. The 24th SLAOP Meeting took place in Bogotá, 4-5 April, bringing together psycho-social professionals and CCFs. At the same meeting as SLAOP, a National Meeting of local CCFs was held that included round table discussions with the National Inter-Institutional Observatory on Childhood Cancer and governmental bodies. The presence of ICCCPPO, as an international body, provided added impact to the statements made and concerns raised by the CCFs.

Oceania

Visits were made to Fiji where presentations to parents were made in Suva and Lautoka. At present limited support is offered to children with cancer by the Fiji Cancer Society. Funds raised by the charity WOWS (Walk on Walk Strong) for the support of children with cancer are being held in Trust by the Fiji Cancer Society until such time it is agreed how to utilise these funds. Simon Lala, ICCCPPO board member, is helping to resolve the matter. The parents in Fiji wish to establish a separately registered charity as soon as possible.

The NZ Paediatric oncology team continued its regular visits to the Islands of Fiji, Samoa and Tonga to further train the health professionals in the Islands.

Asia

Kazuyo Watanabe and Carmen Auste visited Huế, Vietnam in June 2012 and July 2013 as part of the on-going on-site mentoring of the newly organised local parents group.

MAHAK, Iran is twinning with Kurdistan Save the Children (KSC) of Iraq which has resulted in the establishment of a dedicated paediatric cancer department at Hiwa Hospital of Sulaimani, Iraq. A parent support group is being organised with the support of KCS. In July 2013, Pau Kwong Wun Charitable Foundation co-organised the 3rd National Chinese Childhood Cancer Patient & Support Group meeting in Wuhan, China. The meeting was attended by over 170 delegates representing 12 regions of China, and over 30 medical professionals. The delegates laid the foundation for building a trusted medical/patient relationship among the participating cities.

Carmen Auste supported Cancer Warriors Foundation in its successful advocacy to get government paid social health insurance coverage for children with leukaemia.

Europe

The 4th ICCCPPO Meeting of European members was held in Basel (Switzerland) from 24 - 26 of May 2013 to discuss European childhood cancer issues and exchange information and experiences. More than 50 parents and survivors from 18 countries attended the meeting. Gilles Vassal, newly elected SIOPE Europe president, spoke about the current situation and future goals of paediatric oncology. In Europe, ICCCPPO works closely with SIOPE in order to harmonise the levels of treatment and care in all European countries. ICCCPPO is partner in the EU funded projects ENCCA, PanCareSurFup, EPOC and IntReALL, where ICCCPPO members are cooperating with physicians on the Survivorship Passport, long-term follow-up guidelines, drug safety and the implementation of the European Standards of Care. ICCCPPO is a member of the Paediatric Committee of EMA. The Parents and Patients Advocacy Committee (PPAC) consists of parent and survivor representatives from eight European countries and has been working with ICCCPPO since April 2012 on issues such as training courses on clinical trials, long-term follow-up care etc. PPAC met for their second face-to-face meeting in Sarajevo from 11-13 July 2013. A conference of the Ukrainian childhood cancer non-profit organisations was held in Kiev 20-21 June 2013 and was organised by Natalia Onipko and Svetlana Shut, where for the first time survivors attended. Irina Ban and Lejla Kamerić facilitated regional cooperation within the Balkan region by visiting Croatian parent groups in Zagreb in November 2012. The Serbian survivors group, "MladiCe", and three Serbian parent organisations (Cika Boca, Uvek sa decom & Zvonica) hosted the first regional convention of childhood cancer survivors from the Balkan region titled "I WANT TO KNOW", in Belgrade from 14-18 August. This meeting was attended by 45 survivors (age 16 to 30) from six countries in the region.

North America

This past year, the American Childhood Cancer Organization (ACCO) partnered with Inspire, their online community support programme, to conduct a second survey looking at the financial impact of the childhood cancer diagnosis on the family. The results clearly reinforce the fact that parents in the U.S. are forced to work less in order to care for their child diagnosed with cancer and that this had a devastating financial impact on half of the families surveyed.

After 10 years of advocacy efforts, Canadian families of children treated for cancer will finally benefit from a new national employment insurance benefit that addresses the very real need of parents to be available to care for their children. It is anticipated that as many as 6,000 families of children with a life-threatening illness or injury, including cancer, will benefit from this important new employment insurance benefit across Canada. All families of children with cancer in North America look forward to the day when a similar benefit will be available for families fighting this disease in all of North America.

COMMUNICATION & INFORMATION

Donations and Sponsorship

ICCCPO has received donations from a number of sources to help with our work.

11 member organisations contributed to the Parents Helping Parents Fund that supports representatives from organisations in low income countries to attend the annual ICCCPO conference. Most members of the Executive Committee donated back their travel reimbursements for regional work. Should you be able to and wish to support our 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 12th consecutive year. Marianne Naafs-Wilstra heads the secretariat, assisted by Patty Brouwer who fulfils 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

Communication via website, electronic newsletter and the social media has become an integral part of the functioning of ICCCPO. In addition to regular updates of the website, seven electronic newsletters were distributed to more than 230 subscribers world-wide. The ICCCPO twitter account, @IntChildCancer, now has 600 followers. The website continues to alert members and the childhood cancer community of ICCCPO to meetings and activities, interesting and innovative projects organised by member groups, survivorship issues and links to scientific and medical information.

UNAUDITED STATEMENT OF FINANCIAL POSITION AS AT 31 DECEMBER 2012

	2012 EUR	2011 EUR
INCOME		
Membership Fees	28,590	27,132
Sponsorship	-	3,204
PHPF	4,990	3,500
Donations	16,128	7,552
Sundry Income	-	3,858
EPOC Grant	9,167	17,309
Int Re All Grant	18,867	-
Hue Project Grant	18,485	-
Interest	2,746	4,376
Total Income	98,973	66,931
EXPENDITURE		
Executive Meeting Costs	13,472	12,928
Audit Fees	750	600
A.G.A. Scholarships	750	3,500
A.G.A. Meeting Expenses	1,222	699
Regional Meetings	18,977	5,435
Bank Charges	874	437
General Expenses	-	57
Advocacy & Lobbying	2,657	3,437
Legal Fees	708	-
Secretariat Expenses	7,200	6,000
Handbook	1,038	-
Hue Project Costs	7,340	-
Int Re All Project Costs	2,793	-
EPOC Expenses	662	4,737
Total Expenditure	58,353	37,830
NET SURPLUS FOR YEAR	40,620	29,101
Transfer from (to) Int Re All Reserve	(16,074)	-
Transfer from (to) Hue Project Reserve	(11,145)	-
Transfer from (to) EPOC Reserve	(8,504)	(10,174)
Transfer from (to) Regional Reserve	(14,692)	(5,000)
NET SURPLUS(DEFICIT) AFTER TRANSFERS	(9,795)	13,927
Fund Balance, Beginning of year	122,582	108,655
Fund Balance, End of year	112,787	122,582
Conference Reserve	11,000	11,000
EPOC Reserve	28,632	20,128
Int Re All Reserve	16,074	-
Hue Project Reserve	11,145	-
Regional Outreach Reserve	23,226	8,534
ORGANIZATION FUNDS	202,864	162,244

COLLABORATION PROGRAMMES

International Childhood Cancer Day

ICCCPO organised the awareness campaign for ICCD on 15 February, 2013, jointly with SIOF. The theme "Early detection ... making a difference" included the early warning signs of childhood cancers, which formed part of the leaflet designed for the day. This year globally more activities took place than ever before, and more than 2000 hits were recorded on the ICCCPO website around ICCD.

ICCSN

At the survivors' session during the annual congress in London around 30 survivors from 17 countries attended the sessions. Sabine Karner and Michaela Willi, were responsible for organising the survivors' programme. In order to further advance the aims of ICCSN, the committee created a handbook "Establishing a survivors group and keeping it going" to encourage the implementation and development of national and local survivors groups. Executive Committee members are: Michaela Willi and Sabine Karner, both from Austria; Jaap den Hartogh and Meike Naafs, both from the Netherlands; and Dorothee Schmid from Germany.

World Child Cancer

World Child Cancer (WCC) was conceptualised and launched as an ICCCPO initiative in 2007 by ICCCPO members at the Annual General Assembly in 2007 and was set up as the fundraising arm of ICCCPO to support projects that would improve the quality of cancer care in developing regions. ICCCPO was allocated sole membership of WCC when it was registered in the UK as confirmation of ICCCPO's role in establishing WCC. Since then the responsibility of running the organisation on behalf of ICCCPO has been entrusted to trustees of WCC. Unfortunately, the majority of WCC trustees recently voted to implement measures to transfer the branding and licencing agreements as well as the operations of WCC to other independent companies. Benson Pau and Kenneth Dollman, Executive Committee members of ICCCPO resigned as trustees of WCC so as not to be part of the committee when the decision was taken. Later Marianne Naafs-Wilstra, honorary member of ICCCPO and founder member of WCC, resigned from the Project Committee of WCC.

ICCCPO and its membership wish to thank the individuals from the developing countries and those who assist them from developed countries for the work they are doing to achieve the objectives of the projects funded by WCC.

My Child Matters

This programme conceived by the Sanofi Espour Foundation and deployed in partnership with the UICC, continues to fund projects involving childhood cancer in developing countries. Since its launch in 2005 the Sanofi Espour Foundation has donated €5.2 million to fund 40 projects in 26 countries. Many of these projects involve members of ICCCPO. ICCCPO Executive Committee member, Kenneth Dollman, and ICCCPO Regional Representative for the USA, Ruth Hoffman, are members of the My Child Matters steering committee.

Building a Partnership with WHO

In October 2012, Kenneth Dollman and Benson Pau met with key WHO officials and in March 2013, they once again met with Dr Oleg Chestnov, the Assistant Director-General (NCD's and Mental Health) and Dr Shanithi Mendis. At the meeting in March further discussions were held around increasing awareness for early diagnosis of childhood cancers and making childhood cancer medicines available and accessible. In addition, thoughts were shared around the inclusion of children, and specifically children with cancer, in the WHO Global Action Plan for NCDs.

Non-Communicable Diseases (NCD) Advocacy

ICCCPO and SIOF jointly forwarded comments to the WHO on the NCD Global Action Plan 2013-2020 on 7 September, 2012 and another on the NCD Framework, Targets and Indicators on 19 October, 2012, with the latter specifically lobbying for inclusion of children and adolescents with cancer which was excluded from the 1st target of a 25% relative reduction in overall mortality of NCDs in the original document. Due to the lobbying efforts of other international NGOs, such as the NCD Alliance, UICC, and others, we are glad to see that the final 9 global targets and 25 indicators adopted by nations at the 66th World Health Assembly in Geneva in May 2013, no longer exclude children and adolescents with cancer. There is still a lot of work to do for ICCCPO and global stakeholders of children and adolescents with cancer in driving advocacy efforts in their own nations to achieve the indicators relevant to children and adolescents with cancer.

UICC - ICCCPO Vietnam Project

A few months after launching the parent group capacity development project, with funding support from UICC, the parents successfully organised the first Family Outing attended by 120 participants and included nursing staff and doctors. The event was supported by other local stakeholders and had multi-media coverage. The parent group is now providing on-going psycho-social support activities in the paediatric oncology wards with the assistance of youth volunteers and the guidance of Kazuyo Watanabe. They also provide support to bereaved parents.

Organization

Fundación Mateo Esquivo
Fundación Natalí Dafne Flexer
Society to Help Children with Cancer
Cancer Council of Tasmania
Childhood Cancer Support Inc.
Children's Cancer Centre Parent Advisory Committee (CCCPAG)
Cure Our Kids Incorporated
Österreichische Kinder-Krebs-Hilfe
Charter of "Fighting Leukemia" public union
ASHIC Foundation
Children Leukemia Assistance & Support Services (CLASS)
Fundación AFANIC
Udruženje "Srce za djecu koja boluju od raka u FBiH"
(The heart for the kids with cancer in FBiH)
Casa de Apoio a Criança com Câncer São Vicente de Paulo
Núcleo de Apoio à Criança com Câncer (NACC)
Association "Children with Oncochaematologic diseases"
b.r.a.i.n.child (Brain Tumour Research, Assistance and Information Network)
British Columbia Childhood Cancer Parents Association (BCCCPA)
Candlelighters Childhood Cancer Support Programs
Childhood Cancer Canada Foundation
Kids Cancer Care Foundation of Alberta (KCCFA)
Kids with Cancer Society Northern Alberta
Ontario Parents Advocating for Children with Cancer (OPACC)
Fundación Nuestros Hijos
Guangzhou Gold-ribbon Children Parents Center
Children's Cancer Foundation
Little Life Warrior Society
Pau Kwong Wun Charitable Foundation
Asociación Alianza para la prevención y el tratamiento del cáncer en el niño-sanar
Colombian Leukemia and Lymphoma Foundation (FCL)
OPNICER
Fundación GiáMaLa de jóvenes para los
Krijesnica (Firefly)
Ljubav na Djelu (Love in Action)
Sanus
Zajedno
Sdružení Šance
Børnecancerfonden
Familier med kræftramte børn (FMKB)
Fundacion Amigos contra el cancer Infantil, Inc. (FACCI)
Jóvenes Contra el Cáncer Fundación
Sol y Vida Fundación
Alexandria Group of Childhood Cancer Care (AGCCC)
Mathiws 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 Gyermekékért
Styrktarfélag Krabbameinssjúkra Barna
Cancer Patients Aid Association (CPAA)
Cankids...kidscan
Eeshwar Child Welfare Foundation (ECWF)
Nivethan
Sahayta Charitable Welfare Society
St. Jude India Childcare centres
Indonesian Care for Cancer Kids Foundation (Yayasan Kasih Anak Kanker Indonesia, YKAKI)
Indonesian Care for Childhood Cancer Foundation (Yayasan Peduli Anak Kanker Manado)
Yayasan Anyo Indonesia (YAI)
Yayasan Onkologi Anak Indonesia (YOAI, Indonesian Childhood Cancer Foundation)
Yayasan Sentuhan Kasih Anak Indonesia
Society to Support Children Suffering from Cancer (MAHAK)
The Cancer Children Organization
Barretstown Camp
CanTeen Ireland
Hayim Association
Associazione Bianca Garavaglia
Comitato Maria Letizia Verga (CMLV)
Federazione Italiana Associazioni Genitori OncoematologiaPediatria (FIAGOP)
Fondazione Cure2Children
Soleterre strategie di pace ONLUS
Asian Children's Care League (ACCL)
Children's Cancer Association of Japan (CCAJ)
Shine On! Kids
Childhood Cancer Initiative
Hope for Cancer Kids (HCK)
CHANCE Association
Children's Cancer Center of Lebanon (CCCL)
Kids First Association
Paguoda
Een Häerz fir kriibskrank Kanner asbl
Fondatioun Kriibskrank Kanner
Peperutka
Children's Cancer Club
Sarawak Children's Cancer Society (SCCS)
Asociacion Mexicana de Ayuda a Ninos con Cancer, I.A.P. (AMANC)
CANICA (Centro de apoyo a ninos con cancer A.C.)

Country

ARGENTINA
ARGENTINA
ARMENIA
AUSTRALIA
AUSTRALIA
AUSTRALIA
AUSTRALIA
AUSTRIA
AZERBAIJAN
BANGLADESH
BANGLADESH
BOLIVIA
BOSNIA HERCEGOVINA
BRAZIL
BRAZIL
BULGARIA
CANADA
CANADA
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CANADA
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CANADA
CANADA
CHILE
CHINA
HKSAR, CHINA
HKSAR, CHINA
HKSAR, CHINA
COLOMBIA
COLOMBIA
COLOMBIA
COSTA RICA
CROATIA
CROATIA
CROATIA
CROATIA
CZECH REPUBLIC
DENMARK
DENMARK
DOMINICAN REPUBLIC
ECUADOR
ECUADOR
EGYPT
ETHIOPIA
FINLAND
FRANCE
FRANCE
GERMANY
GHANA
GREECE
GREECE
GUATEMALA
HUNGARY
ICELAND
INDIA
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JAPAN
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JAPAN
KENYA
KENYA
LEBANON
LEBANON
LEBANON
LITHUANIA
LUXEMBOURG
LUXEMBOURG
MACEDONIA
MALAWI
MALAYSIA
MEXICO
MEXICO

Website or Email

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
mehrban63@mail.ru
www.ashic.org
www.classbd.org, www.facebook.com/classbd
www.fundacionafanic.com
www.srcezadjecu.ba
www.casaapoiocancer.org.br
www.nacc.org.br
www.decaohz.org
www.sickkids.ca/brainchild
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
www.ccf.org.hk
www.hkllws.org/en_index.php
www.pkwfoundation.org
www.sanarcancer.org
www.funcolombianadeleucemiaylinfoma.org
www.opnicer.org
www.giamala.com
www.krijesnica.hr
www.ljubavnadjelu.hr
www.sanus.hr
doria.verbic@ri.htnet.hr
www.sancecz.org
www.boernecancerfonden.dk
www.fmkb.dk
www.facci.org.do
www.jovenescontraelcancer.org
www.solyvida.info
ysaadeldin@gmail.com
www.mathycancersoc.org
www.sylva.fi
www.lenvol.asso.fr
http://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.cancer.org.in
www.cankidsindia.org
http://eeshwarchildwelfare.org/
www.nivethan.org
www.sahayta.org
www.stjudechild.org
www.ykaki.org
lilikarudeng@yahoo.com
http://yai-indonesia.org/YAIWP/
www.yoafoundation.org
www.sentuhankasih.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.soletterre.org
www.accl.jp
www.ccaj-found.or.jp
www.sokids.org
childhoodcancerinitiative@yahoo.com;
omachjoseph@yahoo.com
www.hope4cancerkids.org
www.chancelebanon.org
www.cccl.org.lb
under construction
www.paguoda.org
www.kriibskrankanner.lu
www.fondatioun.lu
www.peperutka.org.mk
emolyneux@malawi.net
www.sccs.org.my
www.amanc.org
www.casacanica.org

Organization

AMAL (Association des maladies atteints de leucémies) see remark at end of line
L'Association L'Avenir

Noujoum	Associação sorriso da criança	Namibia Childhood Cancer Parents Support Organisation (NaCCapso)	Cancer Council Nepal (CCN)
Cancer Society Nepal	Vereniging Ouders, Kinderen en Kanker' (VOKK)	Child Cancer Foundation	Asociación de Padres de Niños Con Leucemia y Cancer (MAPANICA)
Children Living with Cancer Foundation (CLCWF)	Barnekreftforeningen (The Norwegian Childhood Cancer Organization)	Cured Cancer Patients Society (CCPS)	Foundation Smile of Hope (SOH)
Fundación amigos del niño con leucemia y cancer (FANLYC)	MITAI - Asociación de Padres para ayuda a niños con cancer	Asociación de padres de niños con cáncer (ASPANION)	Esperantra (Asociacion de Ayuda al Paciente con Cancer)
Cancer Warriors Foundation Inc	Kythe Inc	Acreditat	Association for Services for Communities Voluntaris of Portuguese-Speaking Countries
Association P.A.V.E.L.	Children and parents against cancer (CAPAC)	ISKORKA	Nadejda
Social Charitable Foundation for Help to Children suffered from leukemia	The Holiday of Life Charity fund	Triedinstvo	ASEAC
"ČIKA BOCA" Childhood Cancer Parent Organization	"ZVONČICA" Childhood Cancer Parent Organization	Udruženje "Uvek sa decom" (Association "Always with children")	NURDOR (Nacionalno Udruženje Roditelja Dece Obolele od Raka)
Rowaca Cancer Group - Sierra Leone	Children's Cancer Foundation (CCF)	JONATAN PRIJATELJ (Jonatan friends)	
CHOC Childhood Cancer Foundation South Africa	Korean Association for Children with Leukemia and Cancer (KACLC)	Federación Española de Padres del Niños con Cáncer (F.E.P.N.C.)	Barncancerfonden
Barncancerfonden Norra	Barncancerföreningen i Stockholmsregionen	Barncancerföreningen Mellansverige	Barncancerföreningen Östra Götaland
Barncancerföreningen Södra	Barncancerföreningen i Vastra Sverige	Kinderkrebshilfe Schweiz	BASMA (BAttling to SMile Again) Chlidren with Cancer Support Association
Child Cancer Foundation of Tonga	The Just Because Foundation	LÖSEV	Bless a Child Foundation
Charitable Fund VIDEN	Childhood Cancer Foundation "Crab"	David Deacon Charity Institution	Ukrainian National Charitable Fund Zaporuka
Childhood Cancer Parents Alliance (CCPA)	CLIC Sargent	American Childhood Cancer Organization	
SuperSibs!	Asociación Venezolana de Padres de Niños con Cancer (ASOVEPANICA)	FTMO (Fundación para el Trasplante de Médula Ósea)	Childhood Cancer Family Group in Central Vietnam (CCFGCV)
Kayula Childhood Cancer Foundation (KCCF)	Zambian Childhood Cancer Foundation (ZACCAF)	Childrens Cancer Relief	

Country

MOROCCO
MOROCCO

MOROCCO
MOZAMBIQUE
NAMIBIA
NEPAL

NEPAL
NETHERLANDS
NEW ZEALAND
NICARAGUA
NIGERIA
NORWAY
PAKISTAN
PALESTINE
PANAMA
PARAGUAY
PERU
PERU
PHILIPPINES
PHILIPPINES
PORTUGAL
PORTUGAL
ROMANIA

RUSSIA
RUSSIA
RUSSIA
RUSSIA
RUSSIA
SENEGAL
SERBIA
SERBIA
SERBIA
SERBIA
SIERRA LEONE
SINGAPORE
SLOVENIA

SOUTH AFRICA
SOUTH KOREA
SPAIN
SWEDEN
SWEDEN
SWEDEN
SWEDEN
SWEDEN
SWEDEN
SWEDEN
SWITZERLAND
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www.childcancer.org.nz
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www.barnekreftforeningen.no
www.thetigerteam.org
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www.barncancerfonden.se/sodra
www.barncancerfonden.se/vastra
www.kinderkrebshilfe.ch
www.basma-syria.org
www.cfft.to
http://thejustbecausefoundation.com

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www.zaccaf.org (UNDER CONSTRUCTION)
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