



MESSAGE FROM THE CHAIR

On behalf of the board it is a pleasure to share this report on the activities and involvement of ICCCPO over the past year.

What makes 2014 especially significant is that we are proud to share that ICCCPO has now been in existence for 20 years. We have come a long way as an organization since 1994 as can be seen from our growth in membership numbers and from the sophistication of the services our members are now able to offer those children and families we serve.

This year has been marked by ever increasing collaborations with other leaders in the field of childhood cancer such as the WHO, SIOP and UICC. The signing of a Memorandum of Understanding with SIOP during the annual conference in Hong Kong set the scene for the year. During the course of the year ICCCPO has been involved and consulted in an ever increasing number of research projects which directly impact on the quality of care of children with cancer and survivors. We also collaborated with UICC and SIOP to produce an early warning sign poster and pocket card for distribution globally. During regional meetings and elsewhere we have assisted the WHO in coming closer to achieving some of their global targets related to awareness creation and pain relief.

It is especially encouraging to see how our survivor organization, ICCSN, is expanding its influence on issues important to survivors.

A special thank you to all those staff and the volunteers who so enthusiastically and with such dedication assist all those affected by childhood cancer: the children, their families, the doctors, nurses, related professionals, the treatment centres and the researchers. In closing, as I complete my term as chair of this great organization, my deepest appreciation goes to the ICCCPO board members and regional committees for continuing to work so tirelessly to achieve our goals.

Sincerely

Kenneth Dollman Chairman

ANNUAL CONFERENCE

The ICCCPO annual conference, in combination with the 45th SIOP annual congress was held in Hong Kong Special Administration Region, China in September 2013. The conference was well attended by over 120 ICCCPO delegates from across the globe who came to share ideas and experiences. ICCCPO held a special day of workshops where delegates from low to middle income countries (LMICs) interacted with those from developed countries. A special fundraising event organized by the Pau Kwong Wun Charitable Foundation assisted 20 medical professionals, mainly nurses, and 15 parents and survivors from LMICs to attend the conference. Donations raised were also used to fund new twinning projects between HICs (high income countries) and LMICs involving ICCCPO and SIOP. As part of the main conference, the survivor group (ICCSN) held their own one day conference, where survivors and delegates shared and learned from the experiences and concerns of those who have survived childhood cancer. Our thanks to Benson Pau who represented ICCCPO on the LOC and to Pau Kwong Wun Charitable Foundation for hosting the ICCCPO Meet & Greet and Annual Dinner. Our thanks also go to the ICCCPO conference committee, chaired by Anders Wollmen, for organising the programme.

ANNUAL GENERAL ASSEMBLY AND MEMBERSHIP

The General Assembly accepted 19 new members – 9 full and 11 associate – from South America (Argentina, Colombia, Costa Rica, Honduras, Mexico) Asia (Indonesia, Iraq, Nepal), Europe (Switzerland, Montenegro) and Africa (Tanzania), with one renewal from Ecuador, Membership of 7 organizations was revoked. This brings membership to 171 organizations from 88 countries.

The General Assembly elected Poonam Bagai (India) and Ruth Hoffman (USA) as members of the Executive Committee, and re-elected Carmen Auste (Philippines) and Edith Grynszpancholc (Argentina). Anders Wollmén (Sweden) stepped down from the Executive Committee and the term of Simon Lala (New Zealand) ended after serving 15 years. Simon Lala was elected as honorary member.

EXECUTIVE COMMITTEE MEETINGS

The first of two meetings was held in Hong Kong (just prior to the Annual Conference) and the second in Valencia, Spain. The latter was generously hosted by Federación Española de Padres del Niños con Cáncer and ASPANION. It coincided with the 20th year founding and anniversary celebration of ICCCPO in Valencia.

20TH ANNIVERSARY CELEBRATION

On 17 May 2014, ICCCPO celebrated its 20th anniversary in Valencia, Spain with the assistance and support of Federación Española de Padres del Niños con Cáncer and ASPANION. As ICCCPO was founded in Valencia, this special milestone was celebrated with three of the original founding members: Jesús Mª González Marín (Spain), Marianne Naafs-Wilstra (The Netherlands) and Gerlind Bode (Germany). More than 100 people consisting of representatives from European parent-and survivors-organizations, the entire ICCCPO board, SIOP's past president, Gabriele Calaminus, several founding and honorary members of ICCCPO, as well as Spanish local and regional politicians, participated in the ceremonial reenactment at the Placa de Pineda, a historical building in the old town of Valencia.

In his speech, Kenneth Dollman, ICCCPO president, emphasized that everyone in attendance were privileged to share with the original founding members the joy and pride of seeing a small organization grow into the organization it is today. From an original 11 member organizations in 1994, ICCCPO has grown to 171 members from 88 countries. All these members are committed and working towards achieving ICCCPO goals by sharing information and experience in order to improve access to the best possible treatment and care for children with cancer everywhere in the world.

Gabriele Calaminus, the immediate past president of SIOP, highlighted in her speech the essential role of parents' organizations and how the commitment of parents made it possible to improve resources in many hospitals, to establish pediatric cancer facilities, fund staff and equipment and make available essential psychosocial support for patients and families. Through pictures and stories, Marianne Naafs-Wilstra vividly captured the history, development and activities of ICCCPO over 20 years.

CONTINENTAL REGIONAL MEETINGS AND ACTIVITIES

Africa

The highlight of the year was the 3rd ICCCPO Africa Regional meeting held in Dar es Salaam, Tanzania in April together with SIOP. The guest of honour was the UICC ambassador for Children with Cancer, HRH Sheika Jawahar Bint Mohammed Al-Qasimi of Sharjah, UAE. For the first time in Africa, traditional healers attended a conference on Western medicine and approaches to the care of children with cancer, where they shared with delegates their approaches. Also in this meeting, the second joint ICCCPO-WHO workshop on pain care management was held. New support groups from Nigeria, Cameroon, Zimbabwe and Malawi have applied for membership of ICCCPO. Current members were very active in translating into their local languages the joint ICCCPO-SIOP-UICC poster on the early warning signs of childhood cancer. Services to families has increased significantly in all countries and new parent homes have been opened in Tanzania and Zambia. National programmes to train home based care workers, traditional medical practitioners, healthcare workers and others in the recognition of childhood cancers and referral systems have been implemented in Zimbabwe by Kidzcan and in South Africa by CHOC Childhood Cancer Foundation. Similar regional programmes are being run in Cameroon and Namibia. An ICCCPO developed African Childhood Cancer website is about to be launched.

Asia

The 7th Asia Regional Meeting with the theme "Go Conquer Childhood Cancer Together" was held in Seoul, Korea in April, with 150 participants from 16 countries in Asia and the Middle East. KACLC (Korean Association for Children with Leukemia and Cancer) an ICCCPO member, prepared an exceptional line up of activities . For the very first time, a WHO-ICCCPO joint workshop on Pediatric Palliative Care and Pain Management was held. Member organizations shared breakthrough innovations in awareness campaigns with media, schools, medical practitioners and government as well as hospital based learning initiatives. KACLC shared successful co-branding campaigns with corporations. For survivors, Japan shared a viable model for health insurance as well as inter-country initiatives for survivors. Singapore showcased its service learning program for survivors which it has undertaken with ICCCPO member organizations in Vietnam and Indonesia. In July, Benson Pau, co-hosted the 3rd National Childhood Cancer Support Groups Conference in Wuhan, China and made inroads in four hospitals in Tianjin and Beijing. These led to the organization of 2 new parent groups. In August, Kazuyo Watanabe of ACCL, Japan co-hosted a pediatric oncology conference in Vietnam. Kazuyo provides assistance to the parents group in Hue as well as Nepal.

Europe

The 5th ICCCPO Regional Meeting of European members was held in Valencia, Spain in May. Around 100 parents and survivors took part in this meeting. The agenda included such topics as ICCCPO/SIOPE collaboration and the need for political advocacy in health issues, updates on EU-related issues, research for new medicines and needs of teenagers and adolescents. The Spanish parent organizations, FEPNC and ASPANION, hosted this meeting. The European Parents and Patients Advocacy Committee Meeting took place after this meeting.

On International Childhood Cancer Day, SIOP Europe and ICCCPO organized a high-level event in the European Parliament with the topic "Tackling inequalities in Paediatric Cancer Care & Research across Europe". Members of the European Parliament (MEPs) agreed to endorse the SIOPE-ENCCA-ICCCPO electoral Manifesto for Paediatric Oncology, a document that unites all stakeholders around concrete objectives in advancing childhood cancer research, treatment and care in Europe.

The SIOPE-ENCCA Conference in Brussels, Belgium, was the first event to address the most urgent issues in paediatric cancer faced by the pan-European research, health, and patient interest groups: integrating new therapies into standard care, improving quality of life of survivors, and abolishing inequalities in access to essential health services and products. During the biannual European Cancer Congress by ECCO (European CanCer Organisations), ICCCPO presented as part of the two-day patient advocacy program and shared an information booth with European survivors' groups. World Cancer Day on the 4th of February was celebrated in the European Parliament in Strasbourg with the launching of the "European Cancer Patients' Bill of Rights" for equal rights and possibilities for cancer patients all over Europe. A new parent group, FENIX, was established in Montenegro by parents of children who were treated in Serbian hospitals. A parent home is being built by "A Heart for Children with Cancer" from Bosnia and Herzegovina in Sarajevo. With the support of ICCCPO members, Cika Boca, Uvek sa Decom and Zvoncica, the Serbian survivors group, MladiCe, hosted the 2nd Regional Convention of Childhood Cancer Survivors from the Balkan region in Belgrade. This meeting brought together 60 young survivors from six countries, namely: Serbia, Montenegro, Croatia, Slovenia, Macedonia and Bosnia and Herzegovina.

Latin America

Across Latin America, the Rotary Initiative for support of children with cancers, which started in Argentina, is growing from strength to strength with more than 20 ICCCPO members now forming partnerships with Rotary clubs. Edith Grynszpancholc, participated at the International Cancer Control Congress held in Peru in November 2013. Perú has developed a Cancer Control Plan, called "Plan Esperanza", which includes more diagnostics for childhood cancers. As a result of the NCD movement, children with cancer in LATAM are receiving more benefits and better care. Fundacion Nuestros Hijos Foundation (Chile), under the umbrella of their External Relations Ministry, started a twinning initiative in Bolivia and Perú with local support groups, the Ministry of Health and a private company. ICCCPO members from Argentina are also assisting Bolivia through interventions such as sending medicines, advocacy actions and capacity building activities with Foundations in the main cities. Two persons, from ICCCPO organization in México and Dominican Republic have joined the LATAM regional committee.

North America

The Kids with Cancer Society (Canada) continues to identify new and innovative programs that they share with other childhood cancer organizations across Canada and around the globe. Programmes include: cancer in the classroom and Brainworks. Val Figliuzzi, former ICCCPO board member was invited to participate with Ac2orn, a newly formed Canadian paediatric cancer advocacy group that is committed to addressing the barriers to paediatric cancer drug development. It also advocates for Canadian researchers and clinicians who do translational research for effective treatments. ICCCPO members from Canada have joined the Canadian Action Network to add the voice of childhood cancer caregivers and support the objectives of 90 patient-oriented cancer organizations across Canada.

Oceania

The independently registered World Child Cancer Charitable Trust in New Zealand had a very productive year. Twinning between NZ and the Islands has been very successful and there has been significant increase in the number of children in the Islands now receiving treatment. During the year, visits were made to Tonga, Samoa and Fiji by doctors, nurses and family support staff. The early warning signs were launched in Samoa and Tonga and by next year, in Fiji. The Tonga Child Cancer Foundation is the only legal parent entity in the Pacific at present, whilst in Fiji and Samoa child cancer support is being provided by the Cancer Society. Simon Lala continues to mentor new parent groups to become stronger advocates for children with childhood cancer in this region.

COMMUNICATION & INFORMATION

Donations and Sponsorship

Support for ICCCPO initiatives have received donations from a number of diverse sources.

10 member organizations contributed to the Parents Helping Parents Fund that supports representatives from organisations in low income countries to attend the annual ICCCPO conference. A number of board members donated back their travel reimbursements to benefit regional outreach.

Generous donations were also received from the Fritz Hiltl Hosenfabrik GmbH & Co in Germany and from the Nordea Investment Funds S.A., in Luxembourg. The Pau Kwong Wun Charitable Foundation, Hong Kong organized a special fundraising event during the annual conference in Hong Kong not only to support medical professionals, parents and survivors from LMICs to attend the conference, but also to support the development of parent groups in China and international twinning projects. Should you be able to and wish to support our work, please contact the Head Office.

· Head Office

ICCCPO wishes to thank the parent organization VOKK, in the Netherlands, for their continued generosity and support in hosting the Head Office for the 13th consecutive year. Patty Brouwer fulfills the role of part-time International Services Manager. ICCCPO is grateful for all that is being done to keep members connected and updated on the activities of the ICCCPO members and other related organizations.

Newsletter, website and social media

Communication via website, electronic newsletter and the social media focuses on informing members and the childhood cancer community about ICCCPO meetings and activities, interesting and innovative projects of member groups, survivorship issues and to provide links to scientific and medical information. Beside regular updates of the website, ten electronic newsletters were sent out to subscribers across the globe. @IntChildCancer is the ICCCPO twitter account and has in excess of 900 regular followers.

COLLABORATION PROGRAMMES

· International Childhood Cancer Day

To help create awareness of childhood cancer, ICCCPO collaborated with SIOP and the Union for International Cancer Control (UICC) to produce a poster for distribution to medical professionals and primary healthcare workers about the Early Warning Signs (EWS) of cancer. The idea is that these posters will be displayed in consulting rooms and other facilities as a visual reminder of childhood cancer. The poster is supplemented by a handy pocket card that can easily be consulted when childhood cancer is suspected. The ICCCPO Head Office worked with the American Childhood Cancer Organization (ACCO) to layout more than 42 translations of EWS posters. These are now available on the ICCCPO website.

ICCSN

More than 30 survivor group delegates from 13 different countries attended the international conference in Hong Kong. The survivors program started with activities organized by survivors from Hong Kong. The conference program was set up and run by Sabine Karner, Michaela Willi, Jaap den Hartogh, Meike Naafs and Dorothee Schmid (ICCSN Committee). The sessions ranged from reports of national survivor groups to presentations held by medical and psychosocial professionals. The European network of survivor groups/-networks increased its collaboration and activities by introducing a secret Facebook group and a special survivors' session at the 5th ICCCPO Europe meeting.

European Union Projects

ICCCPO is partner in a number of EU funded projects. The ongoing projects are ENCCA, PanCareSurFup and IntReALL. Three new EU funded projects have started: GAPP (GAbapentin in Paediatric Pain) that will focus on the development of gabapentin for the treatment of paediatric chronic pain; PanCareLIFE, that will investigate late effects that impact fertility and hearing impairment and assess health-related quality of life; and ExPO-r-Net (European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment) that aims to reduce the current inequalities in survival in Europe by improving the quality of healthcare provided across Europe with a special focus on European countries with lower healthcare capabilities.

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. A new three-year action plan has been decided which focuses on: the evaluation and strengthened accompaniment for 15 current projects in Asia, Africa and Latin America; support for interregional networks; and actions that insure that childhood cancer becomes a public health priority. ICCCPO Executive Committee members, Kenneth Dollman and Ruth Hoffman are members of the My Child Matters steering committee.

Non-Communicable Diseases (NCD) Advocacy

Dr Oleg Chestnov, Assistant Director-General of WHO, was invited to deliver a keynote lecture at the ICCCPO-SIOP annual conference in Hong Kong in September 2013 on developments surrounding NCDs and highlighted the important role childhood cancer support groups could play. Benson Pau attended the high-level meeting of the UN General Assembly on the review of country progress in the prevention and control of NCD on 10-11 July 2014 in New York. Kenneth Dollman and Benson Pau visited Geneva in mid July 2014 to work with WHO on collaborative programs related to the WHO Global NCD Action Plan 2013-2020.

World Health Organization

Kenneth Dollman and Benson Pau once again met with key WHO officials, Dr Oleg Chestnov, the Assistant Director-General (NCDs and Mental Health) and Doctors, Douglas Bettcher, Bente Mikkelsen and Andreas Ullrich. At the meetings further discussions were held on collaborative initiatives involving increasing awareness of childhood cancers and palliative care and how ICCCPO can assist the WHO to achieve its targets relating to childhood cancers.

International Confederation Of Childhood Cancer Parent Organizations AUDITED STATEMENT OF FINANCIAL POSITION AS

AT 31 DECEMBER 2013		
	2013	2012
	Euros	Euros
INCOME		
Membership Fees	37,410	28,590
Merchandise Sales	14,652	77.75
PHPF	11,974	4,990
Donations & Sponsorships Grant - GAAP Project	34,820 854	10,123
EPOC Grant	5,697	662
Int Re All Grant	9,021	2,793
Hue Project Grant	8,531	7,340
Interest	2,575	2,746
Total Income	125,534	57,244
EXPENDITURE		
A.G.A. Meeting Expenses	29	1,222
A.G.A. Scholarships	8,856	750
Advocacy & Lobbying	1,687	2,567
Audit Fees	764	750
Bank Charges	992	873
EPOC Expenses	5,697	662
Executive Meeting Costs	11,946	13,472
GAAP Expenses	854	1.000
General Expenses	2,173	1,038
Hue Project Expenses Int Re All Project Costs	8,531 9,021	7,340 2,793
Legal Fees	182	708
Merchandise Purchases	6,289	700
Regional Meetings	15,017	18,977
Secretariat Expenses	12,000	7,200
Total Expenditure	84,038	58,352
Net Surplus (Deficit) for the Period	41,496	(1,108)
Total Recognised Revenue and Expenses	41,496	(1,108)
GENERAL FUNDS AT START OF PERIOD	112,787	113,895
GENERAL FUNDS AT END OF PERIOD	154,283	112,787
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		www.icccpo.or
Organization	Country	website or email
entro de Apoyo al Enfermo de Leucemia (CENAELE)	ARGENTINA	www.cenaele.org.ar
undación Creando Lazos (FCL)	ARGENTINA	www.creandolazos.org.ar
undación Crisalida	ARGENTINA	fundacioncrisalida@hotmall.com
fundación Mateo Esquivo	ARGENTINA	www.fme.org.ar
undación Natali Dafne Flexer	ARGENTINA	www.fundacionflexer.org
ociety to Help Children with Cancer	ARMENIA	badalyan@doctor.com
hildhood Cancer Support Inc.	AUSTRALIA	www.ccs.org.au/
hildren's Cancer Centre Parent Advisory Group (CCCPAG)	AUSTRALIA	www.rch.org.au/ccc
ure Our Kids Incorporated	AUSTRALIA	www.cureourkids.com.au
sterreichische Kinder-Krebs-Hilfe	AUSTRIA	www.kinderkrebshilfe.at
harter of "Fighting Leukemia" Public Union	AZERBAIJAN	www.leykoz.az
SHIC (A Shelter for Helpless III Children) Foundation for Childhood Cancer	BANGLADESH	www.ashic.org
hildren Leukemia Assistance & Support Services (CLASS)	BANGLADESH	www.classbd.org, www.facebook.com/classbd
indación AFANIC	BOLIVIA	www.fundacionafanic.com
druženje "Srce za djecu koja boluju od raka u FBiH" (The Heart for Kids with Cancer in FBiH)	BOSNIA HERCEGOVINA	www.srcezadjecu.ba
asa de Apoio a Criança com Câncer São Vicente de Paulo (CACCSVP)	BRAZIL	www.casaapoiocancer.org.br
úcleo de Apoio à Crianca com Câncer (NACC)	BRAZIL	www.nacc.org.br
sociation "Children with Oncochaematologic diseases"	BULGARIA	www.decaohz.org
ra,Ln,child (Brain Tumour Research, Assistance and Information Network)	CANADA	www.sickkids.ca/brainchild
itish Columbia Childhood Cancer Parents Association (BCCCPA)	CANADA	www.bcccpa.org
nildhood Cancer Canada Foundation	CANADA	www.childhoodcancer.ca
ds Cancer Care Foundation of Alberta (KCCFA)	CANADA	www.kidscancercare.ab.ca
ds with Cancer Society Northern Alberta	CANADA	www.kidswithcancer.ca
ntario Parents Advocating for Children with Cancer (OPACC)	CANADA	www.opacc.org
indación Nuestros Hijos	CHILE	www.fnh.cl
hildren's Cancer Foundation	CHINA	www.ccf.org.hk
uangzhou Gold-ribbon Special Children Parents Centre	CHINA	www.jiazhanghui.org.cn
ttle Life Warrior Society	CHINA	www.hkilws.org/en_index.php
the Life Warrior Society bu Kwong Wun Charitable Foundation	CHINA	www.pkwfoundation.org
NAR – Alianza para la Prevención y el Tratamiento del Cáncer en el Niño	COLOMBIA	
		www.sanarcancer.org
olombian Leukemia and Lymphoma Foundation (FCL)	COLOMBIA	www.funcolombianadeleucemiaylinfoma.org
indación La Divina Providencia	COLOMBIA	www.fundacionladivinaprovidencia.org
indación Maria José, Pequeños y Grandes Herores (FMJ)	COLOMBIA	www.fundacionmarlajose.org
PNICER	COLOMBIA	www.opnicer.com
oundation POHEMA (Pediatras Onco-Hernatólogos)	COLOMBIA	www.pohema.org
sociacion Naninu de Padres de niños con Cáncer (NANINU)	COSTA RICA	www.proyectonaninu.com
indación GiáMaLa de jovenes para los	COSTA RICA	www.giamala.com
ijesnica (Firefly)	CROATIA	www.krijesnica.hr
ubav na Djelu (Love in Action)	CROATIA	www.ljubavnadjelu.hr
NNUS.	CROATIA	www.sanus.hr
njedno	CROATIA	
družení ŠANCE	CZECH REPUBLIC	www.sancecz.org
ørnecancerfonden	DENMARK	www.boernecancerfonden.dk
smiller med kræftramte børn (FMKB)	DENMARK	www.fmkb.dk
undación Amigos Contra el Cáncer Infantil, Inc. (FACCI)	DOMINICAN REPUBLIC	www.facci.org.do
SONIC - QUITO	ECUADOR	https://www.facebook.com/asonic.org.ec;
		http://www.asonic.org/
evenes Contra el Cáncer Fundación	ECUADOR	www.jovenescontraelcancer.org
ol y Vida Fundación	ECUADOR	www.solyvida.info
exandria Group of Childhood Cancer Care (AGCCC)	EGYPT	ysaadeldin@gmail.com
athiwos Wondu - YeEthiopia Cancer Society (MWECS)	ETHIOPIA	www.mathycancersoc.org
AVA	FINLAND	www.sylva.fi
ENVOL pour les enfants européens	FRANCE	www.lenvol.asso.fr
nion Nationale des Associations de Parents d'Enfants atteints de Cancer ou Leucémie (UNAPECLE)	FRANCE	http://unapecle.medicalistes.org
eutsche Leukämie-Forschungshilfe (DLFH)		www.kinderkrebsstiftung.de
	GERMANY	
hana Parents Association for Childhood Cancers (GHAPACC)	GHANA	www.ghapacc.org
oga - Parents Association of Children with Cancer	GREECE	www.floga.org.gr
SO	GREECE	iaso@otenet.gr
indación Ayúdame a Vivir	GUATEMALA	www.ayuvi.org.gt
ndación Hondureña para el Niño con Cancer (Honduras Foundation for children with cancer)	HONDURAS	www.salvamivida.org
ırópai Tāmogatāsi Egyesület a Rákos Gyermekekért	HUNGARY	www.euroonko.de
yrktarfélag Krabbameinssjúkra Barna	ICELAND	www.skb.is
incer Patients Aid Association (CPAA)	INDIA	www.cancer.org.in
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Kayula Childhood Cancer Foundation (KCCF) VIETNAM http://ccfgvietnam.googlepages.com/ ZAMBIA www.kayulachildhoodcancer.org Zambian Childhood Cancer Foundation (ZACCAF ZAMBIA www.zaccaf.org Childrens Cancer Relief (Kidzcan) ZIMBABWE www.kidzcanzimbabwe.org

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