

THE INTERNATIONAL CONFEDERATION OF CHILDHOOD CANCER PARENT ORGANIZATIONS



MESSAGE FROM CHAIR

Welcome to the ICCCPO Annual Report 2010 - 2011. After attaining the UN ECOSOC Special Consultative Status in July 2010, ICCCPO has reached out to even more organizations internationally. ICCCPO is in contact with SIOP, UICC, WHO, and UN with the idea of establishing closer ties internationally.

On 15th February 2011, the chairs of ICCCPO and SIOP had a meeting in Bonn, Germany to discuss further collaboration between the two organizations. Afterwards, ICCCPO joined SIOP at a press conference organized by Deutsche Kinderkrebsstiftung to promote International Childhood Cancer Day (ICCD) and to raise the awareness of childhood cancers.

On 1st April 2011, board members, Kenneth Dollman, Carmen Auste and myself visited the Geneva Office of the World Health Organization (WHO) to explore a closer working relationship between WHO and ICCCPO. Both parties continue to work towards achieving this goal. On the same day, we also visited UICC to discuss collaboration on some joint projects.

On 16th June 2011, two board members, Kenneth Dollman and Edith Grynszpancholc, prepared a case for childhood cancer at the informal interactive hearing on non-communicable diseases at the United Nations in New York where they were joined by ICCCPO member American Childhood Cancer Organization represented by Ruth Hoffman. The informal hearing was in preparation for the high level UN General Assembly on Non-Communicable Diseases at the same venue on 19th & 20th September 2011.

Dr Gerlind Bode of Germany, one of our Honorary Members, was invited by the European Commission: Health and Consumers Directorate in June 2011 to join the Paediatric Committee as a patient representative on behalf of ICCCPO.

Without exception, this year all members and continental representatives remained actively involved with ICCCPO activities. On behalf of ICCCPO, I would also like to express my sincere gratitude to all our members who are participating so enthusiastically in increasing awareness of childhood cancer to the benefit of families worldwide. At the same time, I would like to extend my appreciation to all board members for their dedication and support in growing ICCCPO.

Sincerely,

Benson Pau Chairman

RASM Pau

ANNUAL CONFERENCE

The Annual Conference of ICCCPO was held successfully in Boston in conjunction with the 42nd SIOP Conference in October 2010. This was the first ICCCPO conference held in the USA since ICCCPO was launched in 1994. The SIOP-ICCCPO conference was well supported with the number of delegates who attended exceeding 2 000. We hope that from this conference, more willingness will be shown from American parent groups to join hands with ICCCPO to support the international childhood cancer network. Special thanks to Anders Wollmen, Anita Kienesberger, Val Figliuzzi - ICCCPO program Chair & Committee, Nancy Stratton and Christine Reilly of the ICCCPO Programme Local Organizing Committee, as well as Dr Lisa Diller - the Chair of SIOP Local Organizing Committee for the immense effort they put into organizing the ICCCPO part of the conference.

EXECUTIVE COMMITTEE MEETING

The EC holds meetings twice each year. In October 2010, the EC met in Boston prior to the Annual Conference, where after the midyear meeting was held in March 2011 in Reykjavik, Iceland, generously and expertly hosted by SKB Iceland.

ANNUAL GENERAL ASSEMBLY & MEMBERSHIP

The Annual General Assembly accepted 11 new members - 5 full and 6 associate members - from four new countries: Iraq, Mozambique, Sierra Leone, and Uganda. ICCCPO also lost 5 members who have not been contactable for a long time. This brings our membership to 138 member organisations from 81 countries.

The Annual General Assembly elected Carmen Auste from the Philippines to the Executive Committee and re-elected Simon Lala from New Zealand and Edith Grynszpancholc from Argentina. Anders Wollmén from Sweden had to step back temporarily due to personal circumstances. Ira Soelistyo of Indonesia stepped down from the board after serving on the Executive Committee for 8 years.

The nomination of Professor Mark Chesler of the USA as Honorary Member of ICCCPO for his outstanding contribution to childhood cancer was unanimously accepted at the AGA.

CONTINENTAL/REGIONAL MEETINGS & ACTIVITIES

Africa

A major focus area continues to be to identify parents, and others sympathetic to the cause of childhood cancer, to start parent support groups attached to treatment centres in areas and countries where none exist. Kenneth Dollman paid a visit to the Cameroon, which has resulted in three new parent groups being formed in this country alone. New groups formed last year are already creating an improved awareness of childhood cancer in their countries. Since October 2010, other new parent groups have been established in Tanzania, Nigeria and Senegal. Potential new groups could be established soon in Lesotho, Botswana, Zambia, Rwanda and Côte d'Ivoire.

Many more countries in Africa 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.

Discussions with Groupe Franco-Africain d'Oncologie Pédiatrique (GFAOP) continue to identify areas of possible future co-operation and support to assist children with cancer and their families in Africa.

Kenneth Dollman has been attending the meetings of the LOC organising the joint SIOP/ICCCPO Africa 2012 meeting. He together with CHOC South Africa have had various meetings to plan a training workshop for delegates from parent groups in Africa in March 2012.

Asia

ICCCPO's footprint in Asia continues. Benson Pau visited Malaysia in November 2010 to foster ties with the "Childhood Cancer Caring Society of Kuala Lumpur". In March 2011, he also visited his Indonesian counterparts where it was agreed to participate in the joint SIOP-ICCCPO Asia 2012 meeting.

On 11th-12th June 2011, about 120 participants, with 22 from 6 other Asian countries, attended the ICCCPO 2011 Asia Regional Meeting held in Chengdu, China. ICCCPO organized the event in conjunction with the local parent groups and hospital. The event successfully overcame the language barrier with the help of volunteers, but more importantly, it laid a good foundation for a strong therapeutic alliance between medical professionals and parent groups in China.

Latin America

Due to Edith Grynszpancholc's health problem, she had to slow down during the latter months of 2010, and she could not participate in some national meetings. Despite this, a regional meeting in Guadalajara, México, with representatives from 11 countries in Latin America was organised in September 2010. In April 2011, the SLAOP Meeting was held in Santa Cruz de la Sierra, Bolivia. Many organizations from other cities attended the meeting and a networking vision was agreed. So far, each city has organized meetings with their local childhood cancer organizations, and subsequently, have agreed to have a National Meeting every year.

Europe

Meeting in Bonn:

About 45 participants - parents as well as survivors - came to the second EU-wide meeting of ICCCPO member groups in Bonn (Germany) at the end of May 2011. The meeting was organized by Anita Kienesberger, Gerlind Bode and Marianne Naafs-Wilstra and the theme was "ICCCPO in Europe - Where are we? Where are we going? What can we do?". Prof. Ruth Ladenstein, SIOP-Europe president, introduced the new EU funded project, ENCCA (European Network of Cancer Research in Children and Adolescents), which aims to structure and harmonize clinical trials throughout Europe in order to improve treatment and care as well as access to best treatment in paediatric oncology all over Europe. ICCCPO is involved in several "work packages" of the ENCCA-project, such as "European sustainable strategy for clinical trials in paediatric oncology", "Ethical aspects of clinical trials", "Education and training" as well as "Dissemination activities" and - last but not least - "Quality of survivorship". Parents and survivors have been approached to participate at various levels. One important issue within the "Quality of survivorship" is to design a so-called "Survivors' Passport" - a personalized record of each survivor's medical history. Another new EU funded project, called PanCareSurFup, which aims to harmonise the follow-up care of paediatric oncology patients, started on the 1st February 2011. One of its goals is the design of international guidelines for long term follow-up.

In the context of these and other EU funded projects the collaboration between ICCCPO and SIOP-Europe is going to be intensified in order to pursue common goals within the paediatric oncology scene in Europe.

Meeting in Kiev:

In April 2011 a conference was held in Kiev, which consisted of two parts: one for clinical paediatric oncologists and the other for representatives from non-governmental and volunteer organizations (NGO's). The conference was attended by representatives from the Ukraine, Russia, Belarus, Italy and Austria. Among the guests of the conference were 16 representatives of parent organisations. As a result of the conference, the participants postulated a resolution to the Ministry of Healthcare of the Ukraine to lobby among politicians to promote the really important issues of paediatric oncology departments in order to improve the situation for children with cancer. The resolution can be found on the ICCCPO-website.

Irina Cepinac Ban visited a parent organisation in Bosnia & Herzegovina on 15th February 2011 to support their ICCD fundraising event and share her project experiences in Serbia. She invited another newly established parent organisation in Belgrade, Serbia to become an ICCCPO member in March. After attending the conference in Kiev in April 2011, she also joined Anders Wollmén in May 2011 to attend a conference in Turkey to support the "International Week for Children with Leukaemia" there.

North America

Considerable research has taken place to identify parent support groups in North America. The results of this research revealed that in Canada only 10 active groups exist. In the USA the challenge has been to contact key individuals to record updated information on the various parent support groups that exist across the country. A major challenge continues to be convincing USA groups of the benefits of membership in ICCCPO, how we as developed countries can erase geographic boundaries and support children in areas where assistance is required.

Efforts continue to be made to reach out to parent groups to provide support and encourage membership in ICCCPO.

COMMUNICATIONS & INFORMATION

Donation & Sponsorship

ICCCPO continues to receive support in various forms from a number of members. Their contributions are not limited to monetary donations, but also include services-in-kind. Special acknowledgement of thanks goes to Barncancerfonden Sweden for sponsoring our Annual Conference for the 3rd consecutive year, and to those other member organisations for their donations to support regional work. Eleven member organisations donated to the Parents Helping Parents Fund. The Parents Helping Parents Fund supports representatives from organizations in low income countries to attend the annual ICCCPO conference.

Your generosity and support is important to the future development of ICCCPO. If you want to support our work, please contact the Secretariat for details.

COLLABORATION PROGRAMMES

EU Projects

The EU-funded Childhope project in which ICCCPO had an active role was successfully concluded in November 2010. In cooperation with paediatric oncology experts within Europe, ICCCPO is presently involved in several EU-funded projects which aim to improve the treatment and care of children with cancer. More information about these projects can be found under the following abbreviations: EPOC, PanCareSurfUp, ENCCA and IntReALL.

STATEMENT OF INCOME, EXPENDITURE & FUND BALANCE FOR THE YEAR ENDED 31 DECEMBER 2010 2010 2000

31 DECEMBER 2010	2010 EUR€	2009 EUR€
Revenue		
Childhope Income	12,743	8,000
Donations	4,960	5,238
Donations- Board Members	5,534	-
EPOC Grant	-	12,083
Interest	2,490	1,218
Membership Fees	28,371	32,301
PHPF	10,173	10,400
Sponsorship	6,350	6,150
Sundry Income	1,167	-
Total Revenue	\$71,789	\$75,390
Expenses		
Advocacy & Lobbying	1,328	1,359
AGA Meeting Expenses	3,295	5,760
AGA Scholarships	4,700	9,683
Anniversary Book	-	3,800
Audit Fees	600	600
Bank Charges	1,021	1,036
Childhope Expenses	14,316	16,244
EPOC Expenses	1,317	814
Executive Meeting Costs	12,013	8,628
General Expenses	59	320
Regional Meetings	13,220	13,058
Secretariat Expenses	6,182	5,844
Total Expenses	\$58,050	\$67,145
Net Surplus For Year	13,739	8,245
Opening Fund Balance	119,405	111,160
Closing Fund Balance	\$133,144	\$119,405

Newsletter & Website

A new ICCCPO logo has been designed with a more colourful and modern look, with our motto "We Care, We share" featuring prominently. A special thank you to the Austrian Childhood Cancer Organisation, who organized the new design. Based on the new logo, a new ICCCPO website was developed by OnlineBase in the Netherlands as a donation in-kind and was launched in the beginning of 2011. With the new website having been launched, communication with members and the interested public has become much easier again. The newest step in this information-package is the electronic newsletter for which interested groups and individuals can sign up.

Secretariat

ICCCPO wishes to thank the parent organization VOKK in The Netherlands who have hosted the Secretariat for the tenth consecutive year. Marianne Naafs-Wilstra heads up the secretariat, with Patty Brouwer as part-time assistant. They keep all members informed of activity and developments by email on a regular basis and can be reached at icccpo-secretariat@vokk.nl

UICC - My Child Matters

As a partnership between the Sanofi Espour Foundation and UICC, the My Child Matters campaign is one of the largest initiatives involved in fighting childhood cancer in low- and middle-income countries. This MCM initiative has grown from supporting 14 projects in 2006 to supporting 22 projects in 2010 thanks to the generosity of the Sanofi Espour Foundation. A number of projects are working together with ICCCPO members to address the gap that exists in survival rates between children with cancer in resource-rich and resource-poor countries. We hope this programme will continue to receive funding as the impact of the MCM projects continue to make a real difference in the early diagnosis, treatment, care and support of children in the developing countries.

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

World Child Cancer

World Child Cancer, which was set up by ICCCPO in 2007 to help children with cancer in low and middle income countries, is going from strength to strength. In 2010 the charity helped over 1,000 children by increasing access to improved diagnosis and treatment and optimising the provision of palliative care. World Child Cancer facilitates and funds medical twinning partnerships linking hospitals in developed and developing countries. These partnerships transfer vital expertise and skills to improve survival rates and overall care for children with cancer. The importance of good quality family support is recognised within all of World Child Cancer's projects as an essential way of reducing the high rates of abandonment of treatment in low and middle income countries. Benson Pau, Marianne Naafs-Wilstra, Simon Lala and Kenneth Dollman (World Child Cancer Trustees) provide valuable advice and guidance in this respect. charity has six operational projects in Ghana, Malawi, Mozambique, The Philippines, Mexico and Colombia and projects are in development in Bangladesh, Namibia, Cameroon and the Pacific Islands. The charity has benefited from the generosity of ICCCPO groups from around the world and is very grateful for the support it has received.

WEBSITE OR EMAIL **MEMBERS COUNTRY** Fundación Natalí Dafne Flexer **ARGENTINA** www.fundacionflexer.org Fundacion Mateo Esquivo ARGENTINA www.fme.org.ar Society to Help Children with Cancer ARMENIA badalyan@doctor.com Cancer Council Tasmania AUSTRALIA www.cancertas.org.au Childhood Cancer Support Inc. **AUSTRALIA** www.ccs.org.au/pages/index.php Cure Our Kids Incorporated **AUSTRALIA** www.cureourkids.com.au Österreichische Kinder-Krebs-Hilfe **AUSTRIA** www.kinderkrebshilfe.at AZERBAIJAN Charter of "Fighting Leukemia" mehriban63@mail.ru BANGLADESH **ASHIC** www.ashic.org **CLASS** BANGLADESH www.classbd.org Fundación AFANIC BOLIVIA www.fundacionafanic.com **BOSNIA HERCEGOVINA** Udruženje, The Heart for Kids with Cancer in FBiH www.srcezadjecu.ba Núcleo de Apoio à Crianca com Câncer - NACC BRAZIL www.nacc.org.br BRAZIL Caio Roberts Society (GAP) jroberts@uol.com.br Casa de Apoio a Criança com Câncer São Vicente de Paulo BRAZIL www.casaapoiocancer.org.br Childhood Cancer Canada CANADA www.childhoodcancer.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 Fundación Nuestros Hijos CHILE www.fnh.cl Little Life Warrior Society www.hkllws.org/en_index.php CHINA Pau Kwong Wun Charitable Foundation **CHINA** www.pkwfoundation.org CHINA Guangzhou Childhood Cancer Parents Group www.jiazhanghui.org.cn OPNICER COLOMBIA www.opnicer.org Colombian Leukemia and Lymphoma Foundation (FCL) COLOMBIA www.funcolombianadeleucemiaylinfoma.org CROATIA Sanus www.sanus.hr Zajedno CROATIA doria.verbic@ri.htnet.hr Firefly CROATIA www.krijesnica.hr Sdružení Šance CZECH REPUBLIC www.sancecz.org Børnecancerfonden The Child Cancer Foundation DENMARK www.boernecancerfonden.dk Familier med kraeframte boern (FMKB) DENMARK www.fmkb.dk DOMINICAN REPUBLIC FACCI (Fundacion Amigos contra el cancer Infantil, Inc.) www.facci.org.do 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 **GERMANY** www.kinderkrebsstiftung.de Deutsche Leukämie-Forschungshilfe (DLFH) Ghana Parents' Association for childhood cancers (GHAPACC) **GHANA** lornarenner@gmail.com Floga - Parents Association of Children with Cancer **GREECE** www.floga.org.gr GREECE iaso@otenet.gr IASO Fundación Ayúdame a Vivir **GUATEMALA** www.ayuvi.org.gt HUNGARY Európai Támogatási Egyesület a Rákos Gyermekekért 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 **INDONESIA** www.yoai-foundation.org (YOAI, Indonesian Childhood Cancer Foundation) Indonesian Care for Cancer Kids Foundation INDONESIA www.ykaki.org (Yayasan Kasih Anak Kanker Indonesia, YKAKI) Indonesian Care for Childhood Cancer Foundation **INDONESIA** lilikarundeng@yahoo.com (Yayasan Peduli Anak Kanker Manado) Society To Support Children Suffering **IRAN** www.mahak-charity.org From Cancer Known as "MAHAK' The Cancer Children Organization IRAQ iccpo_iraq@yahoo.com Barretstown Camp IRELAND www.barretstown.org **IRELAND** CanTeen Ireland www.canteen.ie HAYIM - For Children With Cancer In Israel **ISRAEL** www.hayim.org.il Comitato Maria Letizia Verga (CMLV) ITALY www.comitatomarialetiziaverga.it FIAGOP (Federazione Italiana Associazioni Genitori www.fiagop.it ITALY Oncoematologia Pediatrica) 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 KENYA Childhood Cancer Initiative omachjoseph@yahoo.com 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 **I FRANON** petern@inco.com.lb LITHUANIA Paguoda www.paguoda.org A heart for cancer sick children LUXEMBURG www.kriibskrankkanner.lu (Een Häerz fir kriibskrank Kanner asbl) www.peperutka.org.mk MACEDONIA Peperutka MALAWI Children's Cancer Club emolyneux@malawi.net Sarawak Children's Cancer Society (SCCS) MALAYSIA www.sccs.org.my AMANC, Asociacion Mexicana de Ayuda a Ninos con Cancer, I.A.P. MEXICO www.amanc.org CANICA, Centro de apoyo a ninos con cancer AC **MEXICO** www.casacanica.org Avenir Association MOROCCO www.almoustakbal.org

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CLIC Sargent Wilms at home American Childhood Cancer Organization

Supersibs

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Production and printing of ICCCPO Annual Report 2010-11 is sponsored by Pau Kwong Wun Charitable Foundation, Hong Kong SAR, China