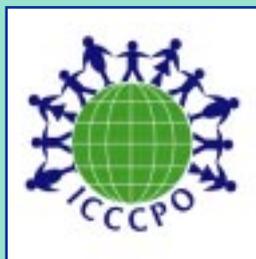
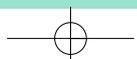


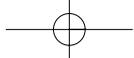
# 2001 ANNUAL REPORT

“To share information and experience in order to improve access to the best possible treatment and care for children with cancer everywhere in the world”



**International Confederation  
of Childhood Cancer  
Parent Organisations**





# Annual Report of the Executive Committee, 2001-2002 (Summary)

**ICCCPO was founded in 1994. It has 54 members representing 43 different countries; 48 are parent run organisations, and 8 are associated.**

## Message from the Chair

It has been another busy and successful year for ICCCPPO, as I hope you will see from this report and the information that will flow from the Annual General Assembly in September. There is still a great deal to be done, but our plans are based on achieving our mission of best treatment and care for children, and their families, everywhere in the world. I believe our growing membership gives ICCCPPO the mandate to represent the global interests of parent and patients, and we will continue to work with organisations such as SIOP to this end.

It has been a difficult year for me personally and so I am grateful for the hard work and support of the Executive Committee and the continuing support of Gerlind Bode, Johan Sandal, Pia Bonini, Rosanna Lupieri and Julian Cutland.

Our mid-year meeting in Monza was a success due to the support of the parent organisation, Comitato MariaLetizia Verga, and the professional team including Giuseppe Masera. I would like to thank the Luxembourg parent group, Een Häerz kriibskrank Kanner, for its dedication in organising the 2001 ICCCPPO conference.

Finally, I would like to thank the Secretariat, and especially Janet Evans, for their support again this year.

## Annual report

Annual Report of the Executive Committee, 2000-2001

The Annual General Assembly 2000 was attended by 24 member nations and ratified the election of 11 new member organisations, representing Mexico, Cuba, Russia, Australia, Bangladesh, Luxembourg, Colombia, Iran, South Africa and Ireland.

The object of ICCCPPO is to help

children with cancer get access to the best possible treatment and care. In practice, the needs of families in each member country differ immensely. In developed countries much effort is now concentrated on psychosocial care – welfare, education, emotional and long-term survivor support. In developing countries, parent organisations are striving to educate doctors and families about diagnosis of cancer, and giving support to help families to travel to a centre, if it exists, for treatment or to buy drugs.

ICCCPO is helping parent organisations against this varied background of needs.

In 2000-2001 the Executive Committee has focused on the following:

## Information & communication

The ICCCPPO Newsletter is the forum for parent organisations to share and communicate. The Newsletter is distributed three times a year by mail and email.

New is the ICCCPPO-Link that gives a flavour of the ICCCPPO newsletter and can be published in local and national newsletters. ICCCPPO-Link is distributed by e-mail.

The ICCCPPO Website – www.icccpo.org has been moved to another server to provide better access and to put more information on it. Work will continue during the coming year to make this a key source of information for members.

The SIOP 2001 conference is in Brisbane in October – too far away, and too expensive for most ICCCPPO members to attend. Therefore, the ICCCPPO 2001 conference is being held in Luxembourg in September, where the parent organisation and Government are supporting the attendance of members from developing countries.

A local ICCCPPO conference has also been organised at SIOP 2001 to maintain the beneficial link of professionals and parents at the same location.

Executive Committee members have been invited to regional meetings and attended whenever possible.

## Increasing membership

Focus this year has been on recruitment in Europe, and new contacts in Arabic and Mediterranean countries, and Africa. The Brisbane conference provides an opportunity to reach out to Asia and the Pacific region.

An up-to-date information base on ICCCPPO members is being developed. Members will be asked to complete a questionnaire in support of this initiative.

The Executive Committee wants as many members as possible retain voting rights, which requires a minimum membership fee. One way to achieve this is through twinning developed and developing countries.

New applications for membership will be presented at the ICCCPPO AGA in September.

## Helping developing countries

- GACCC (Global Alliance for the Cure of Childhood Cancer). ICCCPPO attended a conference of 12 international organisations in February 2001 to look at working together in support of a common cause.

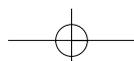
- In South Africa, the parent organisation (CHOC) has worked with professionals on issuing an Early Warning Signs statement to local doctors – with the aim of diagnosing childhood cancer at an early stage. This significant development is supported by SIOP and has worldwide application.

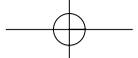
- ICCCPPO supports members with small resources by lowering their fees (on application), offering stipends to attend the ICCCPPO annual and regional conferences, and through twinning. An initiative to extend the work initiated by Giuseppe Masera through the Sponsor a Child programme will be presented at the ICCCPPO 2001 conference.

- ICCCPPO officers are actively involved in planning conferences in Africa, Asia, Latin America, and Eastern Europe.

## Liaison with SIOP

ICCCPO and SIOP work together on a range of subjects:





The mission of ICCCPO is to share information and experience in order to improve access to the best treatment and care for children with cancer everywhere in the world.

The goals of ICCCPO are to:

- Exchange and coordinate information between parent and professional organisations
- Increase public awareness of childhood cancer
- Support the needs of disadvantaged families dealing with childhood cancer
- Represent member organisations at an international level
- Support member organisations in developing their activities
- Generate resources and assets to achieve its aims

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## STATEMENT OF REVENUE, EXPENSES AND FUND BALANCE DECEMBER 31, 2000 > to be adopted

	2000 US\$	1999 US\$
<b>Revenue:</b>		
<b>Membership fees</b>	11,979	9,165
<b>Sponsorships</b>	-	660
<b>Interest and sundry</b>	1,502	916
	<u>13,481</u>	<u>10,741</u>
<b>Expenses:</b>		
<b>Conference</b>	-	7,588
<b>Executive meetings</b>	2,755	2,331
<b>Office and general</b>	49	351
<b>Postage and courier</b>	2,381	3,179
<b>Printing and stationery</b>	1,081	643
<b>Professional fees</b>	707	570
	<u>6,973</u>	<u>14,662</u>
<b>Excess of expenses over revenue</b>	6,508	(3,921)
<b>Fund balance, beginning of year</b>	27,159	31,080
<b>Fund balance, end of year</b>	<u>33,667</u>	<u>27,159</u>

## Summary of goals for 2001/2002

Early Warning Signs guidelines – to provide local doctors with basic advice on identifying signs of childhood cancer for referral to specialists for diagnosis.

Twinning - to develop the Sponsor a Child programme and a range of networking activity.

International Survivors Network – establishing a network to build on the programme at the ICCCPO 2001 conference.

International Childhood Cancer Day – raising awareness, helping local fund-raising, finding a sponsor for ICCCPO at an international level.

Mid-year meeting & regional conference – the mid-year EC meeting to be held in a location that might support a regional conference for developing countries.

SIOF liaison – on Guidelines for Care, Sponsor A Child, and other programmes. The ICCCPO and SIOF 2002 conferences will be held together in Portugal.

ICCCPO membership – working towards a 5-year goal for membership.

## Annual Report continued...

- ICCCPO conferences at international and continental SIOF
- Liaison at the GACCC
- Working on Guidelines for Care
- Liaison on Sponsor a Child programme
- Executive Committee meeting with SIOF leadership
- Talks to build a common internet portal

## Long term survivors

The first international survivors meeting will be held at the ICCCPO 2001 conference in Luxembourg.

The Executive Committee is writing a project on healthy lifestyles for survivors which may receive funding from the European Union.

## PR and Funding

The ICCCPO world poster is produced by CHOC, SA.

The Annual Report is funded by the Lisa Thaxter Trust, UK

Proposals for a Childhood Cancer Day will be presented at the ICCCPO 2001 AGA. The aim is to raise awareness, to support members in their local fund-raising, and to attract

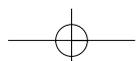
a sponsor to support ICCCPO activities at an international level.

## Internal operations

The Executive Committee met in Monza and Luxembourg.

A Business Plan is being developed to support the differing needs of members. Proposals will be presented at the AGA.

In between meetings we were able to work efficiently through email and through the support of the ICCCPO Secretariat in Canada (courtesy of Candlelighters).



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## The International Confederation of Childhood Cancer Parent Organisations (2000-2001)

COUNTRY	ORGANISATION	MEXICO	MEXICO
AUSTRIA	Confederation of the Austrian Childhood Cancer Parent Organisations <a href="mailto:dachverband@kinderkrebshilfe.at">dachverband@kinderkrebshilfe.at</a>	AMANC—Asociacion Mexicana de Ayuda a Ninos con Cancer <a href="mailto:amanc1@mail.infoabc.com">amanc1@mail.infoabc.com</a>	
AUSTRALIA	Children's Leukaemia & Cancer Society Inc. <a href="mailto:ceo@clcs.org.au">ceo@clcs.org.au</a> Camp Quality Ltd <a href="mailto:campquality@compuserve.com">campquality@compuserve.com</a> (Tasmania) Cancer + Parents Like Us Tel: +61 03 62332030	MOROCCO L'AVENIR - Moroccan Association of Parents and Friends of Children with Cancer <a href="mailto:mokhtar@acdim.net.ma">mokhtar@acdim.net.ma</a>	
BANGLADESH	Children Leukaemia Assistance & Support Services (CLASS) <a href="mailto:class@globalctg.net">class@globalctg.net</a> ASHIC (Shelter) Foundation for Childhood Cancer <a href="mailto:ashic@citechco.net">ashic@citechco.net</a> / <a href="mailto:choudhml@anz.com">choudhml@anz.com</a> NACC - Nucleo ed Apoio a Crianca com Cancer <a href="mailto:nacc@ecologia.com.br">nacc@ecologia.com.br</a>	NETHERLANDS VOKK - Dutch Association "Parents, Children and Cancer" <a href="mailto:mcnaafs.vokk@wxs.nl">mcnaafs.vokk@wxs.nl</a>	
BRAZIL	The "Tashko" Humanitarian Foundation <a href="mailto:tashko@mbox.digsys.bg">tashko@mbox.digsys.bg</a>	NEW ZEALAND Child Cancer Foundation <a href="mailto:info@childcancer.org.nz">info@childcancer.org.nz</a>	
BULGARIA	Candlelighters Childhood Cancer Foundation Canada <a href="mailto:staff@candlelighters.ca">staff@candlelighters.ca</a>	NICARAGUA Asociacion de Padres de Ninos con Leucemia y Cancer <a href="mailto:bidmsina@ibw.com.ni">bidmsina@ibw.com.ni</a> <a href="mailto:Cancer@ibw.com.ni">Cancer@ibw.com.ni</a>	
CANADA	Colombian Childhood Cancer Parents Organization - "OPNICER" <a href="mailto:jabisambra@lasc.com.co">jabisambra@lasc.com.co</a>	NORWAY SKB-Stotteforeningen for Kreftsyke Barn <a href="mailto:johan.sandal@bdc.no">johan.sandal@bdc.no</a>	
COLUMBIA	"SANUS"—Parents & Children Sick or Treated Against Malignant Diseases <a href="mailto:srdjana.culic@st.tel.hr">srdjana.culic@st.tel.hr</a>	PORTUGAL ACREDITAR—Movement of the Portuguese League Against Cancer <a href="mailto:acreditar@acreditar.pt">acreditar@acreditar.pt</a>	
CROATIA	Grupo de Apoyo de Padres de Ninos Oncologicos "El Principito" <a href="mailto:calderon@infomed.sld.cu">calderon@infomed.sld.cu</a>	ROMANIA P.A.V.E.L <a href="mailto:pavel@diol.kappa.ro">pavel@diol.kappa.ro</a> ; <a href="mailto:pavel@ong.ro">pavel@ong.ro</a>	
CUBA	Foraeldreforeningen og Unge me Kraeft <a href="mailto:ff@foraeldreforeningen.de">ff@foraeldreforeningen.de</a>	RUSSIA Parents Against Cancer Plus <a href="mailto:kondrasheva@mail.ru">kondrasheva@mail.ru</a> Children and Parents Against Cancer <a href="mailto:childrencancer@mail.ru">childrencancer@mail.ru</a> Novosibirsk Foundation For Aid to Invalid Children with Oncohematologic <a href="mailto:fond_nadez.da@mail.ru">fond_nadez.da@mail.ru</a>	
DENMARK	Alexandria Group of Childhood Cancer Care (AGCCC) <a href="mailto:ysaad.eldin@yahoo.com">ysaad.eldin@yahoo.com</a>	SOUTH AFRICA CHOC-Childhood Cancer Foundation of South Africa <a href="mailto:cutland@icon.co.za">cutland@icon.co.za</a>	
EGYPT	SYLVA—Association of Parents of Children With Cancer <a href="mailto:syopa.lapset@sylva.inet.fi">syopa.lapset@sylva.inet.fi</a>	SPAIN Federacion Espanola de Padres del Ninos Con Cancer <a href="mailto:federacion@cancerinfantil.org">federacion@cancerinfantil.org</a>	
FINLAND	German Leukaemia Foundation (DLFH) <a href="mailto:dlfhbonn@t-online.de">dlfhbonn@t-online.de</a>	SWEDEN The Children Cancer Foundation of Sweden (Barncancerfonden) <a href="mailto:staff@barncancerfonden.se">staff@barncancerfonden.se</a>	
GERMANY	FLOGA—Parents' Association of Children With Cancer Tel/Fax: +301-7772421	SWITZERLAND Schweizerische Interessengemeinschaft fur krebskranke Kinder <a href="mailto:childhoodcancer@switzerland.org">childhoodcancer@switzerland.org</a>	
GREECE	IASO Tel/Fax: +30-41 550-060	UK National Alliance of Childhood Cancer Parent Organisations (NACCPO) <a href="mailto:thaxter@litrust.freemove.co.uk">thaxter@litrust.freemove.co.uk</a> UK Children's Cancer Study Group <a href="mailto:sea4@le.ac.uk">sea4@le.ac.uk</a>	
ICELAND	The Icelandic Childhood Cancer Parent Organisation (SKB) <a href="mailto:skb@skb.is">skb@skb.is</a>	UNITED STATES Candlelighters Childhood Cancer Foundation <a href="mailto:erhoffman@earthlink.net">erhoffman@earthlink.net</a>	
INDIA	Sahayta Charitable Welfare Society <a href="mailto:sahayta@chi.dot.net.in">sahayta@chi.dot.net.in</a>	VENEZUELA Asociacion Venezolana de Padres de Ninos Con Cancer <a href="mailto:mmarsis@infoline.wtfe.com">mmarsis@infoline.wtfe.com</a>	
INDONESIA	Indonesian Childhood Cancer Foundation <a href="mailto:aptivawaru2@yahoo.com">aptivawaru2@yahoo.com</a>	YUGOSLAVIA "ZVONCICA"—Society for Help of Ill Children Tel/Fax: 381 11 671-122 "Uvek sa decom" - Association "Always with Children" <a href="mailto:rtimotic@eunet.yu">rtimotic@eunet.yu</a>	
IRAN	MAHAK - Charity Society to Support Children Suffering from Cancer <a href="mailto:mahak@kanoon-net">mahak@kanoon-net</a>		
IRELAND	Cancer Plus <a href="mailto:oryan@irishcancer.ie">oryan@irishcancer.ie</a> The Barretstown Gang Camp <a href="mailto:info@barretstowngc.ie">info@barretstowngc.ie</a>		
ISRAEL	HAYIM—for Children With Cancer in Israel <a href="mailto:hayim@clalit.co.il">hayim@clalit.co.il</a>		
ITALY	Comitato Maria Letizia Verga <a href="mailto:pierangelo.bonini@galactica.it">pierangelo.bonini@galactica.it</a> Federazione Italiana Associazioni Genitori Oncoematologia Pediatrica <a href="mailto:fiagop@tin.it">fiagop@tin.it</a>		
JAPAN	Children's Cancer Association of Japan Tel: +81 35228 6105		
KOREA	Korea Association of Children's Cancer and Leukaemia Tel: 02-3444-9032-4 Web: <a href="http://WWW.KOO.NET">WWW.KOO.NET</a>		
LATVIA	Latvian Childhood Cancer Foundation Tel: 371-2-375527		
LITHUANIA	Lithuanian Society of Children with Oncohematological Diseases "Paguoda" <a href="mailto:mmi.ahkit@post.omnitel.net">mmi.ahkit@post.omnitel.net</a>		
LUXEMBOURG	Ern Häerz fir kribbskrank Kanner A.S.B.L. <a href="mailto:nelly.noel@skynet.be">nelly.noel@skynet.be</a> Aide aux Enfants Atteints d'un Cancer		

### Executive Committee

## 2001/2002



Marianne Naafs-Wilstra, chair (The Netherlands)  
Mark Chesler, vice-chair (USA)  
Christine Wandzura, secretary (Canada)  
Simon Lala, treasurer (New Zealand)

Sadie Cutland (South Africa)  
Rogelio Araújo Gil (Spain)  
David Orren (Israel)  
Mokhtar el Harras (Morocco)  
Geoffrey Thaxter (UK)