

“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”

ANNUAL REPORT 2002



**International Confederation
of Childhood Cancer
Parent Organisations**

Annual Report of the Executive Committee, 2002

The annual ICCCPPO conference in 2001 was held in Luxembourg and again proved to be a huge success. It was the first international parent meeting that also involved survivors meeting attended by survivors from around the globe. To celebrate the meeting, twenty-five survivors cycled from Germany to Luxembourg where a public reception was held to acknowledge their achievement.

Our thanks go to Een Haerz fir kriebkrank Kanner for their efforts in making the 2001 conference a success.

The Annual General Assembly was attended by twenty-two member nations and saw the admission of the following new (associate) members: L'Envol (France), Kids Cancer Care Foundation of Alberta (Canada), Fundacion Flexer (Argentina) and CLIC (Cancer and Leukemia in Children - UK).

After many years of faithful service, Sadie Cutland from South Africa retired from the Board and Julian Cutland was elected in her place. Due to personal commitments Rogelio Araujo Gil resigned from the Board. During the past year the EC has been committed to implementing the 2002 ICCCPPO business plan which saw the following achievements::

International Childhood Cancer Day

15 January 2002 saw the launch of the inaugural ICCCD. The purpose of the day was to raise awareness of childhood cancer and to help ICCCPPO member organisations raise funds for their work within their own countries. The day proved a huge success with events taking place in over 30 countries and attracted the attention of the International Media. Around \$100,000 was raised by members for their local work. The event was supported by Cancer Research UK.

Early Warning Guidelines

Guidelines were established to help doctors in developing countries to recognise symptoms of childhood cancer for referral to specialists for diagnosis and treatment. These guidelines have the support of SIOP and have worldwide application.

Twinning and Sponsoring Children in Developing Countries

Active promotion has been undertaken to promote Twinning between developed and developing countries. The co-operation of

health professionals is critical to the success of any twinning programmes.

A *parents helping parents* fund has been established to support attendance at the annual conference in Porto by representatives from developing countries.

Parents Helping Parents Fund

We believe that childhood cancer has no borders and so the Stipend Fund was renamed to more accurately reflect our focus. It is now known as the Parents Helping Parents Fund to reflect that it is ultimately the parents' groups throughout the world that will assist other organizations so that members from less fortunate countries, who cannot afford the cost of travel, may attend the annual conference. Funding for this cornerstone program is also realized from the dues members pay to belong to the Confederation.

To gain the resources necessary to bring parents from all over the world together in 2002, we asked all developed countries for their help. All these contributions pooled together will help to bring many parents together so that we may continue to learn and share from many, diverse points-of-view. We even asked members to make a personal donation.

Standards of Treatment and Care

Guidelines have been drawn up and are under discussion between SIOP and ICCCPPO. It is hoped that these guidelines

can be issued as a joint document in the coming year.

Global Alliance

Partners in the Global Alliance for the cure of childhood cancer have continued to support the Lymphoma treatment in Africa was on the agenda. Existing trials were discussed and ICCCPPO is encouraging the extension of these trials to other African countries to help more children get access to treatment.

Membership

Our aim is to continue to recruit more organisations to consolidate our position as the recognised worldwide body representing the families of children with cancer. Membership rights and responsibilities have been reviewed and these will be promoted on the ICCCPPO website. The collation of in-depth profiling of our members is continuing.

Information and Communication

Much progress has been made in establishing the ICCCPPO website which is now being hosted in South Africa. The ongoing maintenance of the website is essential for benefits to be generated from it by our members or other interested viewers.

The ICCCPPO newsletters continue to be very popular amongst our members and isare another effective means of communication. However our editors are always on the lookout for contributions.

International Library & Bibliography

2001 has been a transition year for the library with the move of the extensive collection within Canada from Ontario to Alberta. Now housed at the Kids Cancer Care Foundation of Alberta in Calgary, Canada, members can avail themselves to the valuable resources published by parent's groups the world over. For a copy of the annotated bibliography you may contact the library host at: wandzura@kidscancercare.ab.ca

South Pacific meeting

The SIOP 2001 conference was held in Brisbane. For the benefit of our members in the South Pacific an ICCCPPO parents meeting was organised. The meeting was

Executive Committee 2002

Marianne Naafs-Wilstra, chair
(The Netherlands)

Simon Lala, vice chair
(New Zealand)

Christine Wandzura, secretary
(Canada)

Julian Cutland, Treasurer
(South Africa)

Mark Chesler (USA)

David Orren (Israel)

Mokhtar el Harras (Morocco)

Geoffrey Thaxter (UK)

The International Confederation of Childhood Cancer Parent Organizations

STATEMENT OF REVENUE, EXPENSES AND FUND BALANCE DECEMBER 31, 2001 > to be adopted

	2001 US\$	2000 US\$
Revenue:		
Membership fees	13,245	11,979
Interest and sundry	584	1,502
Total Income	13,829	13,481
Expenses:		
Executive meetings	3,804	2,755
Office and general	243	49
Postage and courier	1,542	2,381
Printing and stationery	1,476	1,081
Professional fees	300	707
Total Expenses	7,365	6,973
Excess of expenses over revenue	6,464	6,508
Fund balance, beginning of year	33,667	27,159
Fund balance, end of year	40,131	33,667

very successful and attended by over 100 parents. Planning is under way for another ICCCPPO parents meeting to be held alongside the SIOP Asia conference in New Delhi.

Public Relations and Fundraising

The ICCCPPO world poster is being continually updated as more members join.

The International Childhood Cancer Day held on 15 January 2002 proved to be a great public relations exercise raising both awareness and the profile of ICCCPPO.

Fundraising continues to be a challenge for ICCCPPO. The generous sponsorship support of the International

Child Cancer Day by Cancer Research UK was most welcomed and we aim to build on this relationship for the benefit of both organisations.

The publication of this Annual Report has again been sponsored by the Lisa Thaxter Trust Fund and is gratefully appreciated.

To support our fundraising efforts, the board is in the process of developing Case Statements for individual projects that ICCCPPO undertakes.

Fundraising – Case Statement

The quest for resources continues to be a challenge, as the ICCCPPO looks for

the funds necessary to fuel the vital work being done on behalf of the world's parents groups. It is a daunting task especially when adopting the stand that we would not interfere with the fundraising efforts of any county or organization. Since all the work of the Confederation is done on a voluntary basis, we again turned to our hard working volunteer core to provide the expertise necessary to create a Case Statement, which will articulate the needs, goals and the funds necessary to carry out our operations. When completed, this Case Statement will be used to form the foundation of our fundraising operations.

Internal operations

The transition of the Secretariat from Canada to Netherlands has now been fully accomplished.

The Executive Committee met in France in March at L'Envol. The meeting coincided with the inaugural meeting of all the French Parent Groups. The formation of a National Group appears promising. The Executive Committee always welcomes the opportunity to have their meetings hosted by members or potential members.

ICCCPO Annual Conference – Porto Portugal

Our yearly conferences remains a focal point of what the ICCCPPO offers its members by the provision of information through a responsive itinerary of speakers, presentations and collaborative sessions with SIOP. Plans for the 2002 conference for Porto, Portugal began at the September 2001 conference in Luxembourg. A steering committee was struck with membership from the host country and two members of the Executive Committee. The date for the 2002 conference is September 16 to 20, 2002 and participants will enjoy an array of presenters representing parents' programs, professional updates and survivors' issues.

ICCCPO members know and understand the value offered at these once-a-year gatherings. They are much more than simply an opportunity to travel - they are education, networking, sharing and inspiration. Most importantly they offer hope. It provides parents with a very tangible method of getting, first-hand, the knowledge and experience that meetings of the ICCCPPO provide. For all members, this knowledge is then shared throughout the country's groups thereby improving supportive programs within the parents' organizations.

The International Confederation of Childhood Cancer Parent Organisations (2002)

ORGANIZATION	COUNTRY	EMAIL
Fundación Natalí Dafne Flexer	ARGENTINA	funflex@sinectis.com.ar
Camp Quality	AUSTRALIA	campquality@compuserve.com
Cancer Council of Tasmania	AUSTRALIA	lcooper@cancer.org.au
Children's Leukaemia and Cancer Inc	AUSTRALIA	ceo@clcs.org.au
Kinder - Krebs - Hilfe (Dachverband)	AUSTRIA	dachverband@kinderkrebshilfe.at
ASHIC (A Shelter for Helpless Ill Children) Foundation for Childhood Cancer	BANGLADESH	ashic@citechco.net
Children Leukaemia Assistance & Support Services (CLASS)	BANGLADESH	class@globalctg.net
Núcleo de Apoio à Criança com Câncer - NACC	BRAZIL	nacc@elogica.com.br
The "Tashko" Humanitarian Foundation	BULGARIA	tashko@plov.omega.bg
Candlelighters Childhood Cancer Foundation Canada	CANADA	staff@candlelighters.ca
Kids Cancer Care Foundation of Alberta	CANADA	wandzura@kidscancercare.ab.ca
Colombian Childhood Cancer Parents Organization & Relationship Diseases OPNICER	COLOMBIA	jabisambra@lasc.com.co
Sanus	CROATIA	srdjana.culic@st.tel.hr
Grupo de Apoyo de Padres de Niños Oncológicos "El Principito"	CUBA	calderon@infomed.sld.cu
Forældreforeningen Barn og Unge med Kræft	DENMARK	ff@foraeldreforeningen.dk
Alexandria Group of Childhood Cancer Care (AGCCC)	EGYPT	ysaad_eldin@yahoo.com
SYLVA	FINLAND	syopa.lapset@sylva.inet.fi
L'ENVOL	FRANCE	lenvol@aol.com
DLFH (Deutsche Leukämie-Forschungshilfe)	GERMANY	dlfhbonn@t-online.de
Floga - Parents' Ass. of Children with Cancer	GREECE	f2001@otenet.gr
IASO	GREECE	30-41-550-060
Styrktarfélag Krabbameinssjúkra Barna	ICELAND	skb@skb.is
Sahayta Charitable Welfare Society	INDIA	sahayta@satyam.net.in
Indonesian Childhood Cancer Foundation (Yayasan Onkologi Anak Indonesia)	INDONESIA	yoai2008@indosat.net.id
Society To Support Children Suffering From Cancer Known as "MAHAK"	IRAN	mahak@kanoon.net
The Barretstown Gang Camp	IRELAND	ciara.casey@barretstowngc.ie
CHAYIM - For Children With Cancer In Israel	ISRAEL	hayim83@zahav.net.il
Comitato Maria Letizia Verga	ITALY	info@comittatomarialetiziaverga.i
Federazione Italiana delle Associazioni di Genitori di Oncoematologia Pediatrica	ITALY	fiagop@tin.it
Children's Cancer Association of Japan	JAPAN	81-3-5228-6107
Korean Association for Children's cancer and Leucemia	KOREA	
Lithuanian Society of Children With Onkohematological Diseases "Paguoda"	LITHUANIA	paguoda@post.com
Een Haerz fir kribbskrank Kanner a.s.b.l.	LUXEMBURG	icccpo@kribskrankanner.lu
Fondation "Aide aux Enfants Atteints d'un Cancer"	LUXEMBURG	352-319731
AMANC, Asociación Mexicana de Ayuda a Niños con Cancer, I.A.P.	MEXICO	amanc1@terra.com.mx
L'Avenir	MOROCCO	mokhtar@iam.net.ma
Vereniging 'Ouders, Kinderen en Kanker' (VOKK)	NETHERLANDS	bureau@vokk.nl
Child Cancer Foundation	NEW ZEALAND	info@childcancer.org.nz
Asociacion de Padres de Niños Con Leucemia y Cancer	NICARAGUA	incapsar@mtx.com.ni
Stotteforeningen for Kerftsyke Barn (SKB)	NORWAY	skb@krefit.no
Associação Acreditar	PORTUGAL	acreditar@mail.telepac.pt
P.A.V.E.L.	ROMANIA	romania@hotmail.com
Children and Parents Against Cancer	RUSSIA	childrencancer@peterlink.ru
Novosibirsk City Foundation for Aid to Invalid Children With Oncohematologic Diseases	RUSSIA	proskuryakova@mail.ru
Parents Against Cancer Plus	RUSSIA	kondrasheva@mail.ru
CHOC Childhood Cancer Foundation of South Africa	SOUTH AFRICA	cutland@icon.co.za
Federación Española de Padres del Niños con Cáncer	SPAIN	federacion@cancerinfantil.org
Barncancerfonden	SWEDEN	info@barncancerfonden.se
Schweizerische Interessengemeinschaft für Krebskranke Kinder	SWITZERLAND	kinder.krebs@schweiz.org / childhood.cancer@switzerland.org
National Alliance of Childhood Cancer Parent Organizations (NACCPPO)	UNITED KINGDOM	thaxter@ltrust.freeseve.co.uk
United Kingdom Children's Cancer Study Group (UKCCSG)	UNITED KINGDOM	ukccsg@le.ac.uk
Candlelighters Childhood Cancer Foundation	USA	info@candlelighters.org
Asociacion Venezolana de Padres de Niños con Cancer Servicio de Oncología	VENEZUELA	rosybriceno@cantv.net
Uvek sa Decom /Ass. Always with Children	YUGOSLAVIA	jelenabo@eunet.yu / rtimotic@Eunet.yu
Zvonica	YUGOSLAVIA	381-11-671-122