

ICCCPO: We Care We Share



The oldies then



1992: How it all began...

- 🌐 **SIOP Hannover, Germany**
- 🌐 **Host: Gerlind Bode**
- 🌐 **13 countries from Europe**
- 🌐 **Shared Chemo-Kasper**
- 🌐 **First Newsletter**
- 🌐 **Promise to meet again!**



SIOP in Hannover (1992)

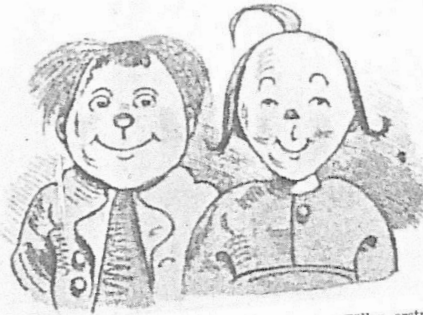
Hannover

HANNOVERSCHE ALLGEMEINE ZEITUNG

Mit Max und Moritz gegen Kinderkrebs k Weltkongreß in Hannover eröffnet / Auch Mediziner aus den ärmeren Ländern und Elterngruppen

Keck grinsen Max und Moritz von der Großleinwand der Stadthalle herab. Zu ihren Füßen haben rund 1000 Kinderkrebspezialisten aus 70 Ländern Platz genommen und warten darauf, daß die Eröffnungsveranstaltung des Weltkongresses der Internationalen Gesellschaft für Pädiatrische Onkologie (SIOP) beginnt. Die beiden weltberühmten Lausbuben aus der Feder von Wilhelm Busch wurden zum Maskottchen dieses Medizinerntreffens bestimmt. „Max und Moritz haben nie aufgegeben – gleichgültig, ob sie vom Bäcker gebacken oder vom Müller gemahlen wurden“, erklärt im Verlauf der Feier Axel Smend, Vorsitzender der Wilhelm-Busch-Gesellschaft. In jedem Menschen, der von der furchtbaren Geißel Krebs befallen werde, stecke in diesem Sinne ein Max oder Moritz, hofft Smend.

Die niedersächsische Wissenschaftsministerin Helga Schuchardt hebt in ihrem Grußwort hervor, daß – wie berichtet – durch das besondere Engagement des hannoverschen Organisationskomitees 160 Wissenschaftlern aus ärmeren Ländern die Teilnahme am Kongreß ermöglicht worden sei. Trotz der großen Zahl von Stipendiaten habe die Nachfrage nicht ganz befriedigt werden können, sagt Schuchardt. Für die geförderten Mediziner hatte am Montag und Dienstag bereits ein Seminar zur Diagnose, Therapie



und Nachsorge von Krebserkrankungen bei Kindern stattgefunden. Der SIOP-Präsident, Professor P. A. Voüte, wies darauf hin, daß der 24. Weltkongreß ursprünglich in Augsburg veranstaltet werden sollte. Nach dem unerwarteten Tod des dortigen Organisationsleiters im Jahr 1989 Professor Hansjörg Riehm im Jahr 1989 Professor Hansjörg Riehm an der Medizinischen Hochschule Hannover (MHH) die Vorbereitung des Treffens übernommen. Voüte dankte dem hannoverschen Chefplaner für seine Arbeit.

Weltweit werde jährlich bei 200 000 Kindern und Jugendlichen Krebs diagnostiziert, beginnt Professor Riehm seine Ansprache. Eine ungewisse Zahl von Erkrankungen bleibe zunächst unerkannt. Die „internationale Familie der Kinderkrebsforscher“ sei in Hannover vollständiger versammelt als je zuvor, freut sich der Organisator. Er begrüßt besonders die 160 Stipendiaten, die in den meisten Fällen erstmals den Industriestaaten sich mit Kollegen aus den hannoverschen Gastländern, die bereit gewesen seien, die Stipendiaten für die Dauer des Treffens bei sich aufzunehmen.

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THE INTERNATIONAL CONFEDERATION OF CHILDHOOD CANCER PARENT ORGANIZATIONS

Newsletter
Vol.2, No.3 (Winter 1995)



A word from the editors

This third edition of the 1995 volume of the ICCCPO Newsletter will hopefully reach you around Christmas. Our topics concentrate more or less on setting up groups. We reprint the lecture Theresa Lanche presented at the parents meeting in Montevideo on founding a support group in a developing country. Our vice chairman, Mark Chesler, has written up some ideas on self help-groups.

We report on the successful parents meeting at the SIOP Conference in Montevideo, Uruguay. There we met with many parents, professionals and volunteers from several South American countries, and we will try as hard as we can to work on these valuable contacts and thus establish a well-functioning collaboration.

We are pleased to announce that the SIOP Conference in Vienna, October 1996, will include a parents meeting in its program (see announcements). We would also like to remind you of ICCCPO's third General Assembly in Denmark next year. We hope to meet many of you at one or both of these meetings.

We are looking forward for your contributions to this newsletter and to ICCCPO's work in general. ICCCPO wants to reach out and get in contact with all parents, especially those who need our support. Therefore we keep asking you to send in information about your groups, your situation and your specific needs and problems.

We also ask your help in spreading this newsletter to groups and hospitals you know in your country as well as abroad. Keep us informed about any change of address and about newly established parents groups. Also send us your translated version of the newsletter, since it might be of great help to other organizations as well.

The next edition of the newsletter (Vol.3, No. 1)

will be published in Spring 1996. Please send your contributions to either of the two editors before March 1, 1995. Meanwhile we wish you a all a wonderful holiday season and a happy New Year!

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Colophon

ICCCPO Newsletter, Volume 2, No. 3
December 1995, Publication: three times a year

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1993

- 🌐 **International meeting Valencia, Spain**
- 🌐 **Host: Jesús Maria Gonzalez Marín**
- 🌐 **16 countries from Europe and USA**
- 🌐 **Work on the constitution**
- 🌐 **SIOP San Francisco, USA**





1994 (1)

- 🌐 **Valencia, Spain**
- 🌐 **Host: Jesús Maria Gonzalez Marín**
- 🌐 **20 countries from Europe, USA and Canada**
- 🌐 **Signing of Constitution by 16 countries**
- 🌐 **Mission statement: „To share information and experience in order to improve access to the best possible care for children with cancer everywhere in the world“**







1994 (2)

 Chair: Jesús Maria Gonzalez Marín

 **Declaration of Valencia:**

All children with cancer should be given the same diagnostic and therapeutic possibilities, a chance to cure.

 **SIOP Paris, France**

 Logo



1995

- 🌐 Chair: Jesús Maria Gonzalez Marín
- 🌐 **AGA Washington, USA**
- 🌐 New: South Africa and Mexico

- 🌐 **SIOP Montevideo, Uruguay**
- 🌐 First workshops
- 🌐 First hospital visit



Candlelight Walk to Capitol





1996

- 🌐 Chair: Kurt Hansen
- 🌐 AGA Århus, Denmark
- 🌐 **SIOP Vienna, Austria**
- 🌐 ICCCPO programme integrated in the official programme



SIOP Vienna



1997

- 🌐 Chair: Kurt Hansen
- 🌐 **AGA Johannesburg**, South Africa
- 🌐 Decision to follow SIOP if feasible

- 🌐 **SIOP Istanbul**, Turkey
- 🌐 Working relations with SIOP psychosocial committee and PODC
- 🌐 Started guidelines on various topics



Johannesburg



Turkey



1998

- 🌐 Chair: Mark Chesler
- 🌐 **Frankfurt, Germany**
- 🌐 First travel stipends through the German group
 - ICCCPO opened up to other parts of the world
 - New Zealand, India, Indonesia, Kazakhstan, Japan
- 🌐 SIOP Yokohama, Japan



boardmeetings....







Frankfurt: lectures and workshops



SIOP Yokohama (1998)



1999

-  Chair: Mark Chesler
-  **SIOP Montreal, Canada**
-  First Scholarships through Parents Helping Parent Fund
-  First joined session with PODC



SIOP Montreal



2000

- 🌐 Chair: Marianne Naafs-Wilstra
- 🌐 **SIOP Amsterdam, Netherlands**
- 🌐 First official representation on SIOP Local Organizing Committee
- 🌐 **First Meet & Greet**
- 🌐 Systematic working relations with SIOP
- 🌐 First joined session with doctors and nurses



Amsterdam: Meet & Greet



Amsterdam

 The board



2001

- 🌐 Chair: Marianne Naafs-Wilstra
- 🌐 **Luxembourg, Luxembourg**
- 🌐 First survivors programme
- 🌐 First Interactive Session
- 🌐 Adoption International Childhood Cancer Day
- 🌐 First ICCCPO Membership Poster
- 🌐 www.icccpo.org
- 🌐 **SIOP Brisbane, Australia**



THE INTERNATIONAL CONFEDERATION OF CHILDHOOD CANCER PARENT ORGANISATIONS

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Sponsored by the Henk Nash Memorial Fund, The Netherlands

2008 Member nations

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

PARENT GROUPS
 - Started in North America and Japan in 1970 and in Europe in the 1980s
 - Increasing acceptance of role of Parent Organizations
 - Initially with local focus, later at national level
 - Increased need to share information across borders

FOCUS AREAS
 - Liaison
 - Advocacy and Education
 - Assistance to Parent Groups
 - Cooperation with non-developed countries
 - Provision of information

LIASON
 - Close affiliation with the International Society for Pediatric Oncology (SIOP) in Continental Affiliates
 - Recognition on a world-wide and local basis
 - Accepted as the voice of the parents
 - Networking with medical and professional world-wide
 - Collaboration with Global Alliance for Childhood Cancer (GACC)
 - World Health Organization (WHO)

ADVOCACY and EDUCATION
 - Creating awareness on Survival Issues
 - Distribution of Medical Services, Employment
 - The Role of Parents
 - The Needs of Family and Siblings
 - School Issues
 - The Needs of Buried Parents
 - International Childhood Cancer Day - 15th February

PROVISION OF INFORMATION
 - Newsletter
 - The Resource Center and bibliography contains a wide variety of educational material in several languages
 - Web site: www.iccco.org

SUPPORT FOR DEVELOPING COUNTRIES
 - Training
 - Travel Scholarships to Meetings
 - Networking
 - Guidelines for SIOP to assist in establishing standards of care in developing countries
 - Recruitment of Parent Groups
 - Creation of a broader network with greater relevant experience

HISTORY
 - Initial discussion in 1982 in Houston, founded in Valencia, Spain (1984)
 - Subsequent Assembly meetings held in Washington DC (1985), Leuven, Belgium (1986), Ljubljana, Slovenia (1987), Frankfurt, Germany (1988), Montreal, Canada (1989), Amsterdam, Netherlands (1990), Oslo, Norway (1991), Poznan, Poland (1992), Seoul, Korea (1993), Istanbul, Turkey (1994), Hong Kong (1995), Sydney, Australia (1996), London, UK (1997), London, UK (1998), London, UK (1999), London, UK (2000), London, UK (2001), London, UK (2002), London, UK (2003), London, UK (2004), London, UK (2005), London, UK (2006), London, UK (2007), London, UK (2008)



SIOP Brisbane (2001)



2002

- 🌐 Chair: Marianne Naafs-Wilstra
- 🌐 **First ICCD**
 - Fundraising and media package
- 🌐 **SIOP Porto, Portugal**
- 🌐 Guidelines on Treatment and Care (adopted by SIOP)
- 🌐 Early warning signs
- 🌐 Promotion of Twinning



SIOP Porto (2002)



2003

- 🌐 Chair: Marianne Naafs-Wilstra
- 🌐 **Barretstown, Ireland**
- 🌐 Survivors board established
- 🌐 **First regional conference in Asia**
- 🌐 **First regional conference in Latin America**
- 🌐 Chapter in ,Surgery of childhood tumours‘
- 🌐 We did not attend SIOP Cairo, Egypt because of the situation in the Middle East

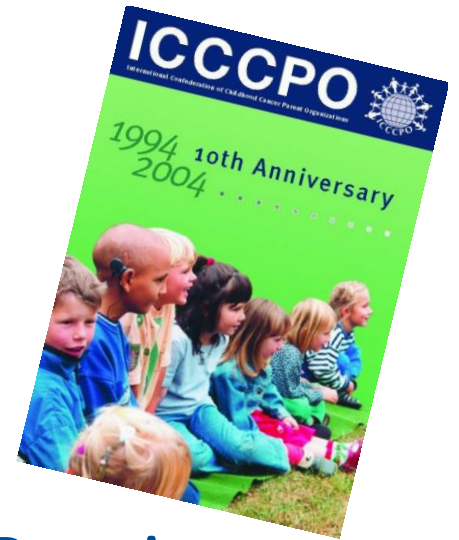


Barretstown (instead of Cairo)



2004

- 🌐 Chair: Simon Lala
- 🌐 Celebration 10th Anniversary in Valencia
- 🌐 **Tenth Anniversary Book**
- 🌐 **SIOP Oslo, Norway**
- 🌐 Appeal to the UN
- 🌐 Meetings of ICCCPPO, SIOP and UN
- 🌐 First regional conference (former) Russian republics



Celebrating ten years in Valencia



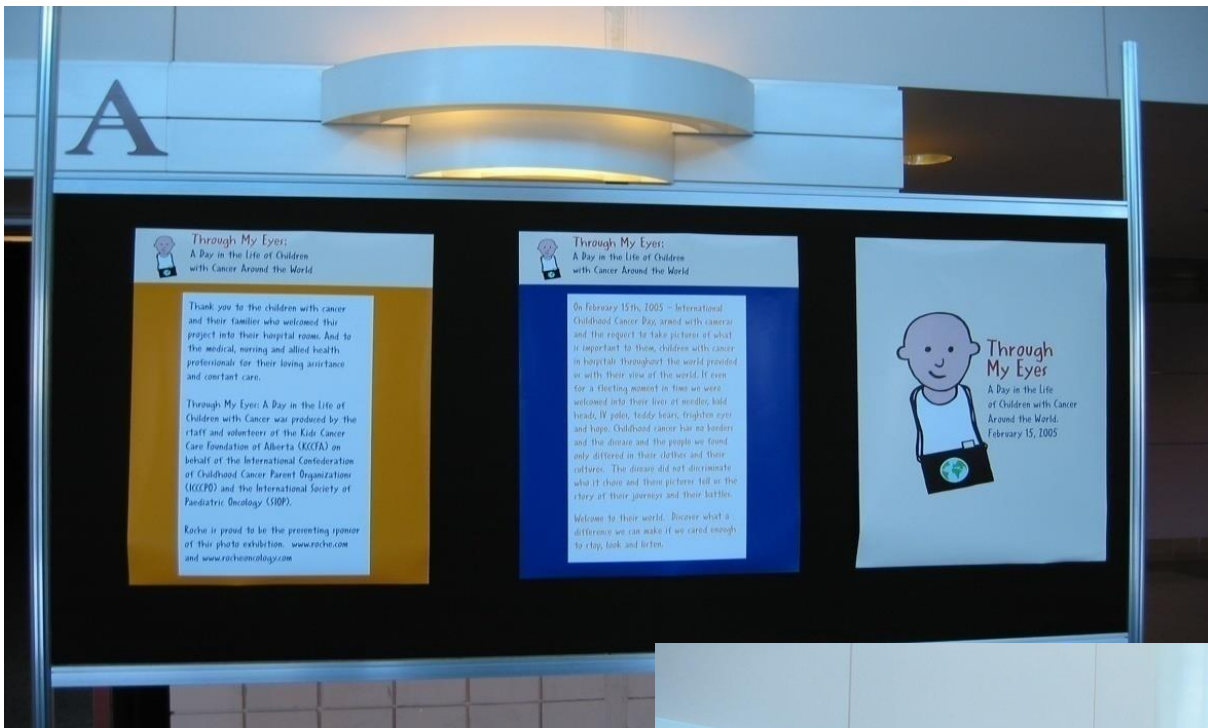
Oslo



2005

- 🌐 Chair: Simon Lala
- 🌐 **SIOP Vancouver, Canada**
- 🌐 **First Through My Eyes**
- 🌐 SIOP/ICCCPO appeal to WHO about the **essential drugs list**
- 🌐 First regional conference of Balkan states
- 🌐 Strengthen **coalition with SIOP Europe**





SIOP Vancouver



2006

- 🌐 Chair. Simon Lala
- 🌐 **SIOP Geneva, Switzerland**
- 🌐 Collaboration with UICC and My Child Matters



Through My Eyes:
A Day in the Life of Children with Cancer Around the World
"Cancer In The Classroom"

On February 15th, 2006 - International Childhood Cancer Day - Children with cancer around the world, armed with cameras and a request to take pictures of what is important to them, snapped photos in their schools and shared with us their view of the world for one day. School is where children learn and play and no matter where they are in their cancer journey, friends and learning are key to helping them to feel normal again. We can witness what their "school world" looked like for a brief moment in time and discover that our children differ only in their clothes and culture.

Welcome to their world. Discover what a difference we can make if we only care enough to stop, look and listen.



2007

- 🌐 Chair: Geoff Thaxter
- 🌐 **SIOP Mumbai, India**
- 🌐 Launch World Child Cancer
- 🌐 First time partner in a EU project
- 🌐 Erice Statement on survivorship
- 🌐 First time co-author of scientific article





Mumbai



2008

- 🌐 Chair: Benson Pau
- 🌐 **SIOP Berlin, Germany**
- 🌐 First „**Meet the experts**“ session
- 🌐 First regional conference Africa
- 🌐 ICCCPO Handbook „Your group is not alone“



Berlin (meet the experts)

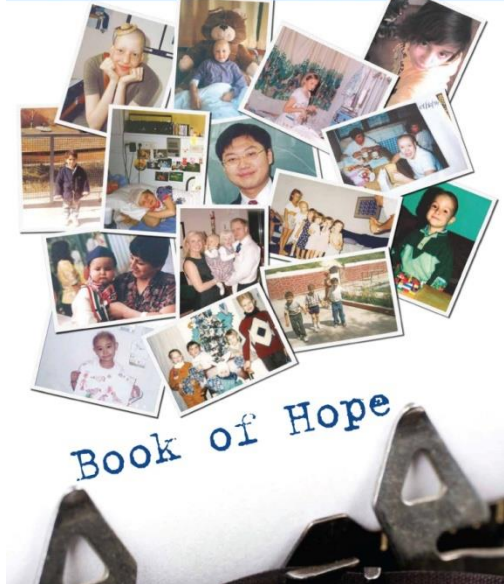




2009

- 🌐 Chair: Benson Pau
- 🌐 **SIOP Sao Paolo, Brazil**
- 🌐 We Care We Share
- 🌐 15th Anniversary
- 🌐 **Book of Hope**
- 🌐 First projects World Child Cancer
- 🌐 Steering Committee My Child Matters





2010

- 🌐 Chair: Benson Pau
- 🌐 **SIOP Boston, USA**
- 🌐 First national Chinese meeting
- 🌐 First European meeting



SIOP Boston



2011

- 🌐 Chair: Benson Pau
- 🌐 **SIOP Auckland, New Zealand**
- 🌐 New Logo
- 🌐 New website
- 🌐 First digital newsletter



Auckland



2012

- 🌐 Chair: Kenneth Dollmen
- 🌐 **SIOP London, United Kingdom**
- 🌐 Formation of the PPAC in Europe
- 🌐 Twitter @IntChildCancer
- 🌐 Hue Project
- 🌐 Collaboration NCD Child
- 🌐 Building **partnership with WHO**
- 🌐 Joint ICCCPO-WHO leaflet





Message from the World Health Organization

In September 2011, Heads of State and Government committed themselves to integrating noncommunicable diseases – including cancers – into health-planning processes and the national development agenda of each country. They also agreed to promote increased access to cancer screening programmes.

The hardship endured by children with cancers is often concealed – and thus perpetuated – by the statistical averages on which health and development programmes and decisions about resource allocation are based. Fortunately, cancers in children constitutes a small percentage of all cancers. However, the most frequent childhood cancers, such as lymphomas and leukemias, are highly curable if detected early and proper diagnostic and treatment procedures are made available. The majority of children with potentially curable cancers can get cured even in low-resource settings, and all children with advanced cancer can benefit from pain relief and palliative care. Children's rights cannot be fulfilled and protected unless preventing and treating cancers is included as a priority within national cancer control programmes.

Today, several low- and middle-income countries, despite facing numerous economic and social challenges, are able to demonstrate success in the implementation of well-organized programmes. This is due to result-based collaborative efforts between governments, civil society, academia and research centres aimed at supporting the provision of services for the prevention, treatment and care, including palliative care, of cancers.

Together with NGOs such as ICCCPo, WHO is strongly committed to supporting national efforts to control childhood cancers in low- and middle-income countries and to reach all children in need, wherever they are excluded and left behind. If we overcome the barriers that have kept these children from the services that they need and that are theirs by right, then more will grow up healthy and realize their full potential.

Dr Oleg Chestnov
Assistant Director-General

About ICCCPo

The International Confederation of Childhood Cancer Parent Organizations (ICCCPo) is a global, parent driven organization that works in partnership with international organizations, governments, policy makers, civil society organizations, health and medical professionals to raise awareness and create support for childhood cancer initiatives. It also makes the case for prioritizing childhood cancer and making it an integral part of the global and national health and development policy agenda. ICCCPo builds and enhances the capacity of parent organizations, particularly in low and middle income countries.

Member Countries

It is a network of organizations currently representing 147 parent organizations in 81 countries. Essentially ICCCPo is a family of engaged, passionate, caring individuals and professional organizations to whom childhood cancer is personally important.

Argentina	Czech republic	Iceland	Malawi	Peru	Switzerland
Armenia	Denmark	India	Malaysia	Philippines	Syria
Australia	Dominican republic	Indonesia	Mexico	Portugal	Tonga
Austria	Ecuador	Iran	Morocco	Romania	Trinidad & Tobago
Azerbaijan	Egypt	Iraq	Mozambique	Russia	(west indies)
Bangladesh	El salvador	Ireland	Nepal	Senegal	Turkey
Bolivia	Ethiopia	Israel	Netherlands	Serbia	Uganda
Bosnia hercegovina	Finland	Italy	New zealand	Sierra leone	Ukraine
Brazil	France	Japan	Nicaragua	Singapore	United kingdom
Canada	Germany	Kenya	Nigeria	Slovenia	United states
Chile	Ghana	Lebanon	Norway	South africa	Venezuela
China	Greece	Lithuania	Palestine	South korea	Vietnam
Colombia	Guatemala	Luxembourg	Pakistan	Spain	Zimbabwe
Croatia	Hungary	Macedonia	Paraguay	Sweden	

Vision

Every Child with Cancer Deserves a Chance



1
Increasing awareness for early diagnosis of childhood cancers

2
Making childhood cancer medicines available and accessible

3
Improving pain care management for children with cancer



THE INTERNATIONAL CONFEDERATION OF CHILDHOOD CANCER PARENT ORGANIZATIONS



www.icccpo.org

2013

- 🌐 Chair: Kenneth Dollmen
- 🌐 **SIOP Hong Kong, China**
- 🌐 Parted from World Child Cancer





Membership

 1994: 11 members from 11 countries

 2014: 171 members from 88 countries





we care, we share

www.icccpo.org



INTERNATIONAL CONFEDERATION OF
CHILDHOOD CANCER PARENT ORGANIZATIONS