



Children's Cancer Day in Croatia (pg. 3)



INTERNATIONAL CONFEDERATION OF CHILDHOOD CANCER PARENT ORGANIZATIONS

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Message from the Chair

I am sure everyone agrees that the death of Geoff Thaxter, our late Chair, is a great loss to ICCCCPO and WCCF. Geoff's dedication to families of children with cancer will always be remembered.

In early October we had a highly successful ICCCCPO conference in Berlin, in conjunction with the SIOP annual congress. It was an excellent opportunity for members and friends to share ideas and enjoy the atmosphere of the ICCCCPO family. I would like to thank everyone who contributed, including Professor Guenther Henze, Gerlind Bode, Prudence Walker-Cuttance, Alexandra Browsdon, Dorothee Schmid, Maren Boesel, and Chrissy Randall. Last but not least, co-chairs Anders Wollmen and Anita Keinesberger.

ICCCPO membership has grown again this year. We now have 118 members from 73 countries, including new members Chile, Ethiopia, Ghana, Nepal, Syria, Tonga, Trinidad & Tobago, and Zimbabwe. I would like to welcome them all and convey my gratitude to those who keep working hard to nurture new groups and recruit new members. This enables ICCCCPO to give a strong voice to families and parent organisations throughout the world.

While the organisation is growing, we have kept our focus on our mission: to improve access to the best possible treatment and care for children with cancer everywhere in the world. These are our major goals for the coming year:

- To foster a "we care" and "we share" culture
- To strengthen our continental and regional work
- To ensure continuity of ICCCCPO
- To build on our advocacy and external relationships
- To keep developing the World Child Cancer Foundation (WCCF).

We are collaborating with SIOP in a therapeutic alliance to speak about the needs and inequality around the world. While we build a network of continental and regional representatives, we look forward to working more closely with SIOP Africa, Asia and Europe, and SLAOP.

The development of WCCF will be essential for ICCCCPO's further progress. WCCF will start funding two projects shortly. Having some successful cases is vital for further international public fundraising, but it will take time.

Together we can make WCCF a strong organisation that makes a real difference to the families of children with cancer in developing countries. If you would like to make a donation to WCCF, please contact Jo Hopkins (jo.hopkins@worldccf.org), Director of Fundraising, or Marianne Naafs-Wilstra (wccf@vokk.nl), Trustee of WCCF & Secretariat of ICCCCPO.

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Contact ICCCCPO

ICCCPO Secretariat
c/o VOKK
Schouwstede 2B
3431 JB Nieuwegein
NETHERLANDS

Produced by CLIC Sargent
(United Kingdom)
www.clicsargent.org.uk

Global Report

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Lastly, I would like to thank Julian Cutland, who has stepped down after 7 years serving the Board. Julian has made an outstanding contribution to the organisation, and his recent work on the Childhood Cancer Foundation Manual has been much appreciated.



Benson Pau, Chair

PS: The ICCCP Board would like to congratulate Poonam Bagai on receiving the Indira Gandhi Priyadarshini Award 2008. This recognises her extraordinary and highly appreciated work for the families of childhood cancer in India.

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The challenges of a shared-care system

I work as a nurse practitioner paediatric oncology and clinical researcher at the Erasmus Medical Centre Sophia Children's Hospital in Rotterdam.

A few months ago, working with one of the paediatric oncologists, I started a project for children with ALL (Acute Lymphoblastic Leukaemia) and their parents. We are trying to improve the care for children and parents through very intensive and efficient cooperation between four shared-care hospitals, where care is shared between the parents, their local hospital, and a paediatric oncology centre.

This is a summary of a lecture I gave to parents, explaining how cancer leads them into a different world, and how to cope with the transition from the oncology centre to the shared-care hospital.

It will also help professionals to understand the journey parents face and how we can help boost their confidence.

Entering a different world

Your 4-year-old daughter is not feeling well. She has occasional headaches, does not want to eat, complains about pain in her legs, and looks pale. After visiting her general practitioner and a paediatrician, you are advised to consult a paediatric oncologist.

Then, 4 weeks later, just as you are adjusting to this new, unfamiliar world, and know your way around the hospital, the outpatient clinic and the day care centre, you are told your daughter needs to transfer to the shared-care hospital in your own area. Another different world.

When the nurse shows you the glossy brochure with photographs of the shared-care hospital, the paediatrician, the nurses and the play-therapist, it increases your confidence, especially when she gives you clear information about the shared-care hospital in a very enthusiastic way. She assures you that cooperation between a paediatric oncology centre and a shared-care hospital is a common policy in the treatment

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of children with ALL. It lets parents take care of their child at home, while staff at your local hospital are informed about your child's disease and treatment, and can call on the paediatric oncology centre if they need more information or backup. But how will your child react to the new doctors and nurses? Are they all just as child friendly as the staff in the paediatric oncology centre? Is the nutritionist's assistant in the shared-care hospital just as kind, and is she serving the food your child prefers?

And what about the lack of specialist expertise? How many children per year do they treat? Is your daughter the first one in this protocol? Will they give your daughter the special attention she needs when her Port-a-Cath is accessed? Do they have the same anti-emetics? Do they administer the chemo in the same syringe or infusion bag? Do they know enough about the side effects of the chemo?

It gives you confidence when the nurses at the paediatric oncology centre put all the information about your daughter in a transfer letter and go through it with you. They tell the nurses and doctors at the shared-care hospital about the special way your daughter's Port-a-Cath needs to be accessed.

The new hospital tells you that they use a different anti-emetic: the Vincristine is delivered by the pharmacist in an infusion bag of 50 ml instead of a 20 ml syringe with 15 ml volume, as it was in the paediatric care centre. It's good to know this in advance, because then you won't assume the difference is because of a lack of expertise. No — it's just another way of doing things.

The nurse tells you that every 8 weeks there is a meeting between staff from the paediatric oncology centre and the shared-care hospital. Every 3 months there is a training course organised by the paediatric oncology centre for the nurses of the shared-care hospital. All this information helps to give you confidence.

Tell the doctors and nurses in the paediatric oncology centre what the transition from their hospital to the shared-care hospital means for you, your daughter and your family. Everybody needs to be aware of the big transitions your family is making.

For all the professionals in shared-care: I hope you will be challenged by this presentation to make shared-care the best care for every child and parent. •

Corry van den Hoed-Heerschop MScN, Erasmus Medical Centre Sophia, Rotterdam

Children's Cancer Day in Croatia

We want to inform you about activities that we arranged around Children's Cancer Day.

We organized the first Croatian Meeting of Young People Cured of Cancer. About 50 young people from all over Croatia gathered in Split. It was beautiful. We talked to members of our government about the problems young people may have after their therapy. The media also attended the meeting so Croatians could hear what the young people had to say. They were very happy and pleased to know that someone cares about their problems. •

“Sanus” Split, Croatia



Global Report

EUROPE

The importance of cancer registries

Article written by Gerlind Bode, Advisor to the Board — from Peter Kaatsch's presentation on Germany Registries at the 2008 Conference in Berlin.

A well-functioning registry is the backbone of any treatment program in paediatric oncology. Exact statistics about the outcome of treatment are the only way to evaluate and adapt therapy protocols. In many countries such registries have existed since the beginning of co-operative trials. In others, this kind of data collection is still at the planning stage.

In some countries, cancer registries are not legally mandatory but work on a voluntary basis. But parents and patients seem to be happy to give their consent if they understand the implications and value of such data.

The parent group "Care for Cancer Kids Foundation" in Indonesia tries to overcome the lack of a national childhood cancer registry by supporting the paediatric cancer ward financially and with manpower. Data collection in the hospital is backed by the personal involvement of members and volunteers who help to locate patients who don't return to the clinic for their follow-ups.

The Swedish Childhood Cancer Registry, a research unit at the Karolinska Institute of Stockholm, provides exact epidemiological data on incidence and survival rates and integrates data from all Scandinavian States in the Nordic Registry.

The German Childhood Cancer registry was established in 1980 and is population based, so trends and cluster developments can be monitored. It works closely with

all German co-operative study groups and hospitals treating children with cancer. Most European registries work closely with ACCIS (Automated Childhood Cancer Information System), a project supported by the European Commission to collect, present, interpret and disseminate data on childhood cancer in Europe. The ACCIS database contains some 160,000 records on childhood and adolescent cancer cases registered over the last 30 years in 78 European population-based cancer registries, covering 2.6 billion person-years. A number of helpful publications can be obtained from ACCIS or the IACRE (International Association of Cancer Registries) as well as practical support in setting up a childhood cancer registry. •

Helpful links:

ACCIS: www.dep.iarc.fr/accis.htm

German Childhood Cancer Registry:
www.kinderkrebsregister.de

Karolinska Institute: www.ki.se

Global Report

EUROPE

Acute lymphoblastic leukaemia protocols in the Netherlands

These are links to helpful articles about the better outcome of paediatric protocols compared with adult protocols.

1) Leukaemia article: Significant difference in outcome for adolescents with acute lymphoblastic leukaemia treated on paediatric vs adult protocols in the Netherlands.

<http://www.nature.com/leu/journal/v18/n12/full/2403538a.html>

2) Paediatric Blood and Cancer:

<http://www3.interscience.wiley.com/cgi-bin/jhome/106561790>

3) British Journal of Haematology:

<http://www3.interscience.wiley.com/cgi-bin/jhome/118517380>

Dr Patty E M Brouwer ICCPO Secretariat, The Netherlands

Setting up the new European Paediatric Hodgkin Network

The EU-funded Paediatric Hodgkin Network starts work in September.

Because of the limited experience with Paediatric Hodgkin's lymphoma in local hospitals, experts from various EU countries decided to create a reference network to fight this rare childhood cancer. Now, young patients with Hodgkin's lymphoma are being treated according to a common protocol in 13 European countries. The primary objectives of this Deutsche Krebshilfe e.V. (German Cancer Aid)-funded EuroNet-PHL-C1 study are high cure rates and significant reduction of late effects, with the least necessary treatment toxicity.

One of the main aims of the project is the creation of a reference board made up of interdisciplinary experts in the fields of oncology, radiology, nuclear medicine and radiotherapy. The attending oncologists submit patients' data, including all original imaging data, to the reference board based in Halle and Leipzig, Germany. The experts assess the tumour stage and treatment

response of every patient, and send the results to the local oncologists, thus providing a second opinion on the treatment decision.

This time-critical process requires modern communication techniques, so we are setting up a European Image Data Network to connect treatment facilities in various European countries. Along with the technical improvements, the EU funding within the framework of the Public Health Programme will allow for a Europe-wide high-quality treatment of all affected young patients, independent of their social or geographical origin.

The project's main partner is the University of Leipzig. Responsible for the project is Professor Dr Regine Kluge, Deputy Director of the Department of Nuclear Medicine, University Hospital, Leipzig. •

Magdalena Kaminska, Project Co-ordinator, European Paediatric Hodgkin Network

Global Report

EUROPE

New websites for Eastern Europe

We'd like to tell you about a new website at www.kids-cancer.info which provides information about local and national parent groups and local hospitals in the countries of former Yugoslavia. There are still some details to be tidied up, but in the meantime the groups and hospitals will be delighted to receive helpful comments and suggestions for improving the site.

In Romania, the PAVEL team has also created a new website at www.asociatiapavel.ro to celebrate the first year of the Centre for Resources and Services for Children and Young People with Cancer and their Families. They were able to create the website as a result of the project they won in the 'My Child Matters' competition.

Irina Ban, Olga Cridland and the PAVEL team

The site is in both Romanian and English, and they welcome contributions and useful articles for and from cancer patients, families, doctors, nurses and psychologists. •

Donations to LÖSEV are transformed into gold

The children of Turkey triumph at the Oncology Olympics.

Our sorrow after the Beijing Olympics was transformed into joy thanks to all the first places the LÖSEV children achieved at the 2nd Oncology Olympics organized by the Orimari Foundation in Warsaw, Poland.

We felt so proud of the great successes of our children, who couldn't suppress their tears of excitement as they won 3 golds in the 3 disciplines in which they competed. This brought great joy and happiness to our country. After their own triumph against the disease, they now raised our flag to celebrate a triumph for our country.

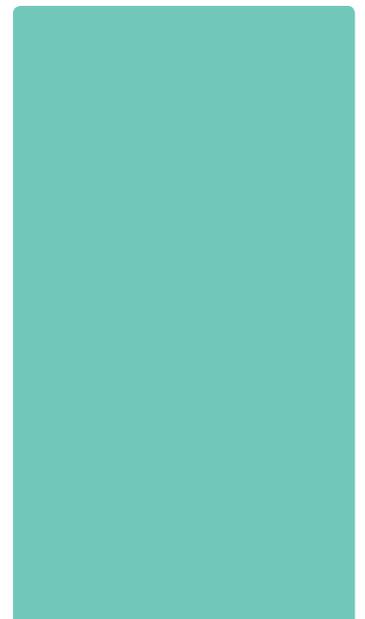
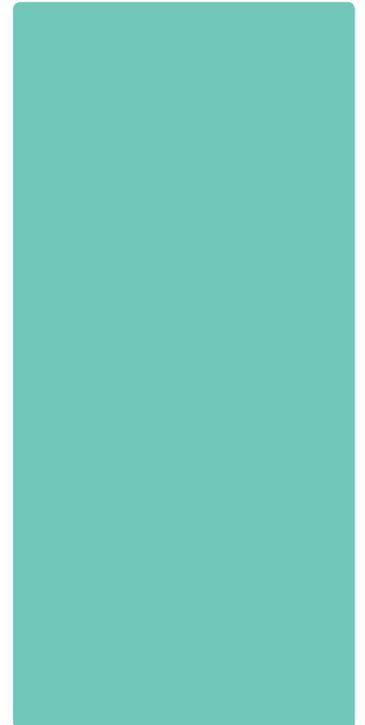
550 children participated in the Olympics, which were organized by the Orimari Foundation. The 8 countries taking part were Hungary, Russia, Poland, Germany, Czech Republic, Slovakia, Ukraine and Turkey.

Nazli MUDUROGLU & Fulya YAVUZ International Relations, LÖSEV

8 children from LÖSEV, aged between 13 and 17, took part in the Oncology Olympics, and their success and determination brought joyful tears to everyone.

Ceren Gökdemýr took first place in swimming and Sadýk Ahmet Güneþ in ping pong. Our soccer team, consisting of Kadir Kaya, Ozan Kurban, Halil Ýbrahim Akgül, Sezer Dýkmen, Uður Yürek and M. Akýn Aras, also won all 3 matches they played, and took the gold medal.

Before returning to Turkey, the LÖSEV delegation visited Turkey's Ambassador in Warsaw, His Excellency Repit Uman, at his residence. •



Global Report

EUROPE

A last wish for Donna

A beautiful young girl made three very special wishes. She left them in a little RED BOX for her young soldier Husband, and Mum & Dad, after she died on New Years Day 1996. Donna Curtis had just turned 20. Donna spent her last four years fighting cancer.

In that time Donna saw the suffering of many terminally ill children, and vowed her instructions would help them live a little more happily in the time they had left.

As her parents, Len & Babs Curtis, made it their love of labour fulfilling their only daughter's fairytale dream as a lasting tribute to her courage (if truth be known, theirs) Len recalls "I was ready to jump off the pier." My family, our businesses, it all suffered. It's a wonder we didn't go under. Instead, we set about making the dream of our late daughter a reality.

Keys were handed over on our 35th Wedding Anniversary, and Donna's Birthday.

A once derelict hotel, has now been converted to a haven for any child to be over-whelmed by. Themed rooms for absolute escapism, Winnie the Pooh's Den, Cartoon World, Teddy Bears World, and Seaside Dream. A must see to believe Circus Room: complete with a steam train encircling the ceiling, a wonderful Disney room.

Local sponsorship allows the whole family to visit all major attractions, free of charge.

A light sensory room and sensory gardens are shadowed by possibly the most poignant room a pretty wooden chapel-like quiet room. This is "where children can be laid to rest, or parents can go to scream". Our honest opinion born by our experiences.

Donna's Dream House is full of light, laughter, fun and most importantly life. Donna's Dream House is about "living not dying".

A heartbreaking fact out of over 500 families who have visited us nearly 400 children have sadly passed away.

Our Donna knew the greatest task set us would help us come to terms with her death, by helping others in a similar situation. •

Global Report

AFRICA

09 Noujoum joins ICCCP

ICPCN launches a Charter of Rights

The International Children's Palliative Care Network (ICPCN) has published a Charter of Rights for children with life-limiting or life threatening conditions, which they wish to see accepted and ratified by governments and health departments around the world.

According to the United Nations Convention on the rights of the child, every child and young person has a right the highest attainable standard of health, as well as the right to be protected against abuse, neglect and all forms of ill-treatment. Governments are required to do everything in their power to ensure that children enjoy full and holistic development.

In the spirit of the UN Convention, the ICPCN Charter sets out the international standard of support that is the right of all children living with life-limiting and life-threatening illnesses, and their families.

The Charter calls for all such children to receive appropriate palliative care — care whose main purpose is to relieve suffering, whether physical, spiritual or emotional, and to promote quality of life.

"A child who dies without receiving adequate pain control and symptom management has suffered abuse — and an untreated HIV positive child is suffering neglect," according to Joan Marston, chair of the ICPCN.

Palliative care encompasses the entire family. It should begin at the time of diagnosis and continue alongside any curative treatment aimed at the disease. If curative treatment fails, palliative care should be continued until the child dies and then with the bereaved family for as long as they need.

The Charter calls for palliative care to be provided within the child's home or a child-friendly environment. It should be

offered by professionals and caregivers trained in palliative care specific to the needs of children.

"Our fervent wish is that this Charter will prove to be a useful instrument for all those who campaign for improved hospice and palliative care services for children around the world," states Marston.

The ICPCN Charter has been translated into 17 different African and European languages which can be downloaded from the website at www.icpcn.org.uk.

What is the ICPCN?

The International Children's Palliative Care Network (ICPCN) was formed in 2005 to achieve the best quality of life and care for children and young people with life-limiting illnesses, and their families and carers, through networking, advocacy, information sharing, education and research.

It is co-ordinated from within South Africa and chaired by Joan Marston, who works for the Hospice Palliative Care Association of South Africa as the Paediatric Palliative Care Manager. •

For more information about this article please contact:

Sue Boucher,

International Information Officer for ICPCN
Tel: +27 (0)31 765 7295
Cell: +27 (0) 828974420
Email: sue@icpcn.co.za

Joan Marston, ICPCN Chair

Tel: +27 (0)822 964 367
Email: joan@hpca.co.za

Global Report

AFRICA

Noujoum joins ICCCP

Noujoum is a non-profit association based in Casablanca and Marrakech, Morocco, which is dedicated to helping sick children and their families.

We are very proud of being a new member of ICCCP and becoming part of this major and extraordinary solidarity network.

Our daily commitment is to ease the management of childhood cancer by

covering medical costs and providing psychological help. We are deeply convinced that sharing our respective experiences will help us achieve better results and bring more support to children and their families. •

Catherine Sebti, Association Noujoum

Global Report

ASIA

News from Nepal

Cancer Society Nepal (CSN) is very proud to be a member of ICCCPO. As a voluntary charitable organisation, established to create awareness of cancer in Nepal, CSN is still in its early stages. So, like a growing child, it needs love, affection, guidance, suggestions and feedback from all of you.

Amongst other activities, we are focusing our programme on childhood cancer, as today's children are tomorrow's world.

Cancer is a global issue, and it touches us all directly or indirectly. Let's share our ideas and experiences.

What CSN has been doing

Two months ago, Cancer Society Nepal visited the Nepal government hospital for childhood cancer, taking medicine and fruits. The children were very happy to see us, and their parents talked frankly and shared their feelings with us.

Shambhu Prasad Kadariya, Executive Director, Cancer Society Nepal

On 15 November 2008 we conducted a 3-hour childhood cancer awareness programme in a poor village area in Kathmandu. Everyone worked voluntarily, including doctors, nurses, and social workers. 75 children and their parents registered for the programme.

We are also planning to manage an accommodation hospital for childhood cancer patients and their parents. •



India celebrates National Cancer Rose Day

National Cancer Rose Day was originally conceived by Cancer Patients Aid Association [CPAA] as a day dedicated to making cancer patients smile. It has been celebrated on 22 September for the last 14 years in major cities in India. The whole city takes time out to visit cancer patients in different treatment centers, taking gifts, toys, roses and personal messages telling them that they care.

5,000 cancer patients are greeted in 33 different treatment centers in Mumbai, including hospitals, hospices, lodges, radiation centres and sanatoriums. All these centers are decorated with floral arrangements in the early hours, and this beautiful sight greets cancer patients when they wake up. Entertainment programmes for patients are arranged throughout the day, including appropriate film shows, orchestras, parties for young cancer patients, and hymns for the terminally ill.

Celebrities visit wards, giving immense happiness to patients who later tell us that this was the best day of their lives.

Doctors report that they have never seen patients so cheerful during their treatment. Smiles light up their eyes and our hearts. There is no sight more satisfying for us at CPAA than the smile of a young cancer patient. Rose Day manages to make the patients and their relatives forget their agonies and battle with cancer. As part of



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ASIA

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this year's Rose Day celebrations, Anita Peter of CPAA organised a Rose Day Fair for more than 500 cancer patients and their relatives at our centre. The patients played games,

got tattoos and bangles, enjoyed snacks and goodies, and met some of their favourite celebrities. •

Shubha Maudgal, Cancer Patients Aid Association
Anand Niketan, King George V Memorial Infirmary



Peppers

Happiness lying behind mysteries ...
mysteries lying behind happiness.
Darkness lying behind sunshine and
sunshine lying behind darkness.
More the mysteries ... the happiness is
more.

More comes the darkness, more is
the sunshine enclosed in it and more
challenging the life becomes ... more
desirable to live.

But a 'desire', doesn't it sound materialistic?
The lines above, don't they sound a bit
materialistic?

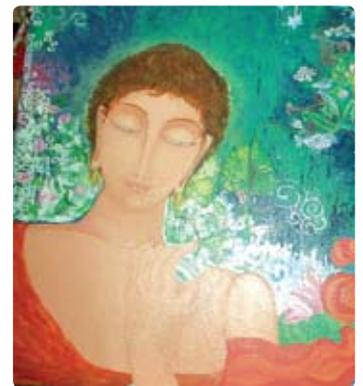
Materialistic? ... then what's real my friend???
These subliming walls and those high,
melting waterfalls?
The fragrance in the air and laws through
Newton's flare?
Beauty in those wet, light grey eyes and the
tick-ticking glare ...

Moments, hours, days and light years,
Sword-like cries and momentous cheers ...

Shobhit Kaushal — Mumbai, India

All so puzzled up, messed up, coiled with
uncertainties of time,
With muddy sun-glasses of ambitions a
deep dive into the hollow brine.
So confused I am, who am I and what for I
am?
But where to look for the answers?
Answers!, so unpredictable.
Queries, questions, goals and desires, all so
irresistible.

But who cares for the answers, and the
questions that gave them birth.
Unknown challenges of life and the life afar,
a deep sigh ... all lost into the last mirth.
But again who cares for the last and the
endless ends.
So challenging, enjoyable is every moment,
life's criss-crossed lanes, its florid tiles with
unknown bends.
Yeah! This is the pepper of my meal.
Amazing becomes every next step, every
new leap with this ageless zeal. •



Interactive CDs for young people with cancer

The Degge Group Ltd of Arlington, Virginia, has developed two award-winning educational interactive CD-ROMs with funding from the National Cancer Institute at NIH. The first one, *Kidz with Leukemia: A Space Adventure (2000)*, is for 4-11 year olds with leukaemia (no reading required for the youngest age group), and the second, *Conquering Cancer Network: Empowering Teens with Tools, Info, and Inspiring Stories (aka CCN) (2006)*, is for adolescents with solid tumors.

These CD-ROMs are designed to help the child and their family. The child with cancer learns that s/he is not alone in the fight against cancer by 'watching' other children like themselves talk about their experiences with cancer, e.g., hair loss. The whole family is helped to understand the illness. Healthcare providers are introduced, coping suggestions are offered, side effects and medications are explained, 'videos' of tests using live patients show what children with cancer have to go through and why they are necessary. All this information helps the patient lead a better quality of life, encourages compliance with the treatment, and thus increases patients' chances to get better.

The evaluation of the CD-ROMs showed that children with cancer who used our CD-ROMs rather than standard printed material were significantly more likely to feel in control of their health from pre- to post-intervention measurement. Evaluation of the *Kidz with Leukemia* CD-ROM showed that children who used it were more satisfied than those with a leukaemia book, with the most positive response reported among 4-6 year-olds. Children used the leukaemia book less often and for shorter periods than those using the CD-ROM.

Voiceovers, music, videos, games, and animations make these CD-ROMs a very interactive medium for learning. The both include a list of resources for the patient and his/her family. The leukaemia CD-ROM

contains a drug database, while CCN has drug fact sheets on various chemotherapy drugs. CCN also has a section on 'Late Effects', which helps the adolescent and the family understand the potential problems s/he could face as a result of cancer treatment, and ways in which s/he can try to avoid some of them or deal with them.

Healthcare providers also like using these CD-ROMs as teaching tools for both patients and their residents/fellows in Haematology-Oncology training. Many would like to give these CDs free of cost to their cancer patients, so they can learn about their illness and treatment at their own pace, in the privacy of their own homes.

Both these multimedia CD-ROMs have been very well-received. So far, Degge has sold 843 copies in 16 countries and distributed more than 470 copies worldwide. However, although we receive frequent enquiries about the CD-ROMs, many people hesitate to buy them because of the cost.

Degge's goal has always been to get sponsorship, so that every child and adolescent with cancer can get a copy of these educational products, regardless of cost. We want to distribute these CDs directly to children and adolescents who need them, or via not-for-profit childhood cancer organizations, cancer camps, and children's cancer clinics. Each CD costs \$29.95 for families with cancer, or \$39.95 for others. On the occasion of its 20th

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anniversary, Degge is offering an extra 20% discount on these CDs throughout 2008.

You can find out more about the CD-ROMs at www.kidzwithleukemia.com and www.conqueringcancer.net.

Sharmila Kamani, The Degge Group Ltd, Arlington, VA

For questions or offers of sponsorship, please call (703) 276-0067 ext 107 or send an e-mail to info@kidzwithleukemia.com or help@conqueringcancer.net. •

Scholarships for cancer survivors in Alberta, Canada

Twenty-six cancer survivors received a surprise when KCCFA announced the first recipients of the KCCFA Derek Wandzura Memorial Scholarship. They discovered that everyone who applied had been granted a \$1,000 scholarship for studies this fall.

Initially just a handful of young people were to be chosen this year because the fund only had \$5,000 to award. But a \$21,000 donation from Brahma Compression Ltd. brought the amount to \$26,000, allowing all applicants to walk away with a scholarship.

"The calibre of the applicants was so high and their stories so inspiring that we decided to stretch the rules — and the fund — in honour of the inaugural year," said Brahma president Don Schafer, who chairs the scholarship committee.

The Kids Cancer Care Foundation of Alberta established the award last winter in honour of Derek Wandzura, the late son of Christine Wandzura, founder and CEO of KCCFA. Derek passed away from brain cancer at age nine: "I wasn't able to see Derek reach the age of these kids here today," said Christine at the awards ceremony, "And I won't be able to see him become a police officer like he wanted but I can see these kids reach their dreams — and that inspires me."

The scholarship is designed to help financially strapped families and level the playing field for young people suffering from the late effects of cancer and its treatments. These may include blindness, deafness, unsteady gait, loss of limbs, small stature, learning difficulties, heart impairments, depression and a host of life-threatening diseases. Young people undergoing cancer treatment also miss more school than their peers and may fall behind academically.

The \$100,000 endowed fund is managed by The Calgary Foundation and its annual disbursement is \$5,000, which is 5% of the total fund. KCCFA hopes to increase that amount in coming years, so the fund remains open to donations.

"We hope to grow the fund substantially next year, so we can give healthy sums to more young people," said Don Shafer. •

To donate to the KCCFA Derek Wandzura Memorial Scholarship fund, visit www.kidscancercare.ab.ca.

Gail Corbett, Manager of Communications, Kids Cancer Care Foundation of Alberta

NORTH AMERICA



Twenty six cancer survivors each took home a \$1,000 scholarship for studies this fall thanks to KCCFA's new scholarship program and a surprise donation from Calgary company Brahma Compression



Derek Rullo receives a congratulatory kiss from his mother. Derek was one of 26 cancer survivors who each took home a \$1,000 scholarship for studies this fall.

PHOTO: Unique Perspectives Artistic Photography

Survivors

International Childhood Cancer Survivor Network (ICCSN)

Contact Report

I hope those of you who could make the conference in Berlin found the programme beneficial and were able to take back new information and ideas to organisations in your own countries. I would like to extend my thanks to Dorothee Schmid, Maren Bösel and Christine Randall, for all their help in organising the survivor programme this year, and especially to Alexandra Brownsdon for chairing the survivor programme in Berlin.

In 2009 the conference will be held in Sao Polo Brazil, and we would love to hear from you if you think you can help plan the survivor programme. The survivor programme each year is intended for childhood cancer survivors and siblings of survivors aged 18 years or over who currently play a roll in survivorship activities in their own country, or who would like to establish such activities. If you would like more information about the survivor programme, please email me.

Prudence Walker-Cuttance

Chairperson, International Childhood Cancer Survivor Network

We are currently looking to strengthen the survivor committee, and I would be delighted to hear from anyone who thinks they have some skills that could help us out. We are looking for anyone (not just survivors or their siblings) with skills that could help our efforts to support the establishment and further development of the International Childhood Cancer Survivor Network, as well as the network and development of survivor groups around the world.

If we get a good idea of what skills people have, we can use each individual's skills to strengthen the committee and help us support survivor groups or those wishing to establish survivor groups.

If we don't have contact with your survivor group, or you would like to start a survivor group, please contact me and we can share some information. •

Our Survivor Group in Mainz

One topic discussed at the survivor meetings in Oslo and Vancouver was "Building up a Survivor Group". I was a member of the Survivor Group in Heidelberg (Germany) for quite some time, and after I had heard so much about assembling a Survivor Group, I thought it would be nice having one in Mainz (Germany), the town were I was treated.

So I talked to the social pedagogue (Mr. Leimig) from the Parents Organisation in Mainz. He also thought it was a good idea to have a Survivor Group in Mainz.

After we had sorted out the most important points, we held our first meeting in June 2006.

If everything goes well we meet once a month. We do lots of different things together, and there are always between five and fifteen teenagers at each meeting. Our group is not just for cancer survivors, but also for siblings and bereaved siblings. "Through the group you have the chance

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Survivors

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to meet friends (from the ward) outside the clinic, and stay in contact.” That’s what a

girl from our group said and I think that’s the point.

Christine Randall



Care to Wear® web shop

Opened online November 19th 2008

Care to Wear® headwear is made for children who suffer from hair loss due to chemotherapy or alopecia. We only use 100% natural fabrics. The construction of Care to Wear® caps and bandanas is specially made:

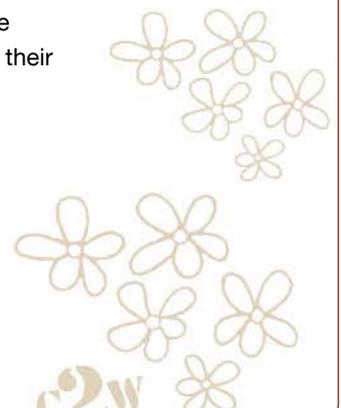
This means that:

- The scalp can breathe
- Care to Wear® caps and bandanas always stay in place
- It covers the back of the head entirely and hides the hair loss
- It gives protection against the harmful rays of the sun

Although special, Care to Wear® headwear resembles “normal” headwear in its design. Children do not want to stand out because they are different! So on the outside Care to Wear® looks like something their friends would wear, too.

We are opening our web shop, by request of parents. We are taking a step towards making it much easier for the children and their parents to buy Care to Wear®.

➔ www.caretowear.dk



News from The Board

Future meetings

Some ICCCP, SIOP and SLAOP dates for your diaries:

2009

- 2-3 April: Asia Regional ICCCP meeting, Beirut, Lebanon parent meeting. Contact Benson Pau benson.pau@pkwfoundation.org
- June: ICCCP Regional Meeting for former Yugoslavian countries, in Macedonia. Contact Irina Ban ban@yubc.net
- August: ICCCP Regional Meeting for Russian speaking groups, Ukraine. Contact Irina Ban ban@yubc.net
- 4-5 October: SLAOP Sao Paolo, Brazil. Contact Edith Grynspancholc, edith@fundacionflexer.org
- 6-9 October: SIOP Sao Paolo, Brazil. Contact Anders Wollmen anders.wollmen@bredband.net

2010

- 10-12 March: SIOP Asia: Kish Island, Iran
- Date to be confirmed: SIOP Africa, Ghana
- 21-24 October: SIOP Boston, USA
- Date to be confirmed: ICCCP Latin American meeting, Guadalajara, Mexico

2011

- Date to be confirmed: SIOP Auckland, New Zealand

Board Members Contact details:

Benson Pau, Chairman
Block B, 1st Floor, 342 Kwun Tong Road,
Kowloon, Hong Kong SAR China
T: +852 2796 0818
benson.pau@pkwfoundation.org

Anders Wollmén, Vice-Chairman
Skogsveg 6, 981 42, Kiruna, Sweden
T: +46 980 661 36
anders.wollmen@bredband.net

Julian Cutland, Advisor
64 Caledon Street, Brooklands Estate,
Northcliff, Johannesburg, 2195, South Africa
T: +27 11 678 3803 M: +27 83 419 4907
cutland@icon.co.za

Simon Lala, Treasurer
5 Jack Conway Lane (Box 76442),
Manukau City, New Zealand
T: +64 9 555 7785 F: +64 9 262 2132
simon.lala@extra.co.nz

Ira Soelistyo, Member
Jln Waru no 12, Pondok Labu-Cilandak,
12450, Jakarta, Indonesia
T: +62 21 7546804
irasoelistyo@ykaki.org

Irina Čepinac-Ban, Member
Palmotićeveva 25A, 11000, Belgrade, Serbia
T: +381 63 644
108ban@yubc.net

Edith Grynspancholc, Member
Mansilla 3125, 1426, Buenos Aires,
Argentina
T: +54 11 4825 5333
edith@fundacionflexer.org

Anita Kienesberger, Member
Borschkegasse 1/7, 1090, Vienna, Austria
T: +43 1/402 88 99
dachverband@kinderkrebshilfe.at

Kenneth Dolman, Secretary
P.O. Box 2427, Durbanville, 7551,
Western Cape, South Africa
T: +27 21 975 1378
kenneth.dollman@choc.org.za

Marianne Naafs-Wilstra, Secretariat
Schouwstede 2B 3431 JB Nieuwegein
Netherlands
T: +31 30 2422944
mc.naafs@vokk.nl

Gerlind Bode, Advisor
Wallfahrtsweg 13 53115 Bonn, Germany
+49 228 224653
gerlind-bode@t-online.de

Medical News (SIOP)

The care needs of adolescents with cancer

Relationships with sick people are often difficult and need give and take. Physicians must always keep this in mind when working with children or adolescents and their families.

Adolescence is a special time of life because so many changes take place. Even healthy adolescents can have behavioral difficulties and parents can be very worried. There is also an evolutionary break down, a period in which contracting a potentially lethal disease and facing difficult treatment may interfere in their growth and identity process. Adolescents affected by a severe disease may experience stress, depression, pain, extreme frustration, and anger.

Understanding adolescents with cancer

Almost all adolescents and young adults being treated for leukaemia and cancer ask for information and clear explanations about their illness, treatment and long-term effects. They often have questions about their future, and sometimes they demand counseling and request details about the possible effects on their sexuality or fertility [1,2]. Some of them also want guidance about physical exercise and fitness, nutrition, transportation and holidays, as well as information about internet sites for cancer education or appropriate support [3].

The supportive care provided by family and friends plays a very important role in the health status and physical functioning of adolescents [4]. To help them cope and adjust, physicians must provide resources and care programs, together with a psychosocial assessment of the whole family. We need to understand how adolescents feel about their unmet needs in order to facilitate their adjustment and help them avoid post-traumatic stress [5].

Research into coping skills

To communicate their feelings, adolescents

often choose to write an impersonal account of their experiences, using symbolism or fantasy [6,7]. A debilitating disease may aggravate difficulties with their body perception and self-esteem [8,9]. Paying attention to these writings will enhance the physician's understanding and allow a deeper exploration of the adolescent's feelings and ability to cope [10,11].

In any case it is very important that physicians improve their listening skills and learn to recognise and resolve barriers that hinder dialogue. Each adolescent must feel comfortable enough to speak about him/herself [12].

Over the last thirty years in our Department psychologists have acquired experience in the Bone Marrow Transplantation Unit, where long-term strict isolation, the painful conditions due both to the illness and to the diagnostic and therapeutic procedures, and uncertainty about the results, all place a very high degree of stress on youngsters.

The data reveals that the most disturbing facts concern the fragmentation of the ego, fantasies about death and above all about sexual identity (particularly when the donor is of the opposite gender). Some problems are linked to the choice of the donor from among family members or to the forced choice of an unrelated donor.

Several cured patients suffer from persisting psychological distress such as self isolation, failure to engage in problem-solving, behavioral disengagement, psychological distress, and difficulties in coping with uncertainty about the future.

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Medical News (SIOP)

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In conclusion we feel that adolescents may be too old for a paediatrician, and yet too young for an adult practitioner - but they always need special care from physicians and professional caregivers.

Luisa M. Massimo, MD

Department of Paediatric Haematology
and Oncology

G. Gaslini

Children's Research Hospital, Genova, Italy

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Medical News (SIOP)

Introducing the new SIOPE Europe website

We are really glad to inform you that we have now launched the new SIOPE Europe (SIOPE) website and it is ready to receive visitors at: www.siope.eu

After several months of careful construction, essential input and guidance from experts within our SIOPE network, the website has been especially structured to provide easy access to a wide range of news, information and services.

Key features on the SIOPE website include:

Public domain

- General information on the SIOPE office and its activities
- The latest news on paediatric oncology, training courses and job opportunities in research groups/institutions
- Useful links to childhood-cancer related public institutions, research consortia and NGOs.

Subscribers only

- Access to the latest SIOPE internal news, such as meeting minutes from different working groups
- Contact details of professionals engaged in the field of paediatric oncology and clinical trials across Europe
- Summaries reporting on current trials throughout Europe
- The latest information on SIOPE's advocacy at the European level.

Initially, the SIOPE website will publish most of its information within the Public Domain. After a trial period of a few months, certain sections will then become password-protected and will only be accessible for subscribers, who will be issued with personal login/password details.

Please note that we have extensively modified the previous contents, and the information on the site has now been improved, updated and better structured

Please take a tour of our new SIOPE website, particularly the 'Parents and Patients' section. If you have any questions or comments please contact the SIOPE office at: jocelyne.wang@ecco-org.eu

We look forward to receiving your feedback, ideas and comments.

We are also delighted to inform you that the SIOPE September 08 Newsletter is now available on the SIOPE website. To access and download the newsletter, [click here](#).

Kathy Pritchard-Jones, SIOPE President

Guidelines for the pharmaceutical development of medicines for paediatric use

The European Medicines Agency (EMA) has published a concept paper on the 'Development of guidelines on the pharmaceutical development of medicines for paediatric use' (EMA/138931/2008). The document is available on the following page.

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The document is available here:

<http://www.emea.europa.eu/pdfs/human/qwp/13893108en.pdf>

<http://www.emea.europa.eu/pdfs/human/biosimilar/17073408en.pdf>

<http://www.emea.europa.eu/pdfs/human/ewp/111998enrev1.pdf>

<http://www.emea.europa.eu/pdfs/human/ewp/914708en.pdf>

<http://www.emea.europa.eu/pdfs/human/vwp/471703en.pdf>

<http://www.emea.europa.eu/pdfs/human/ewp/1437708en.pdf>

<http://www.emea.europa.eu/pdfs/human/biosimilar/11826407en.pdf>

This concept paper is the first step towards developing scientific and harmonised guidelines for responsibly developing a medicinal product for use in different subsets of the paediatric population.

Anders Blædel Lassen

European Medicines Agency (EMA)

Medical Information Sector

SIOP/ICCCPO Conference

BERLIN 2008

Report from the 40th Congress of the International Society of Paediatric Oncology

It was wonderful to arrive in Berlin and see so many people who were all working towards a common goal — to give a future for all children and young people around the world with cancer and their families.

There were so many different programmes running at the conference, that just understanding the programme was a job in itself, and you felt a bit like, as we say in the UK, “a child in a sweet shop” — so many presentations, speakers and people to talk to who would be interesting and offer more knowledge, that you are not too sure where to start.

As your roving reporter for this year's conference, I have been able to cover nearly all of the parents' conference.

In addition to the parents' conference, I have also been able to share with you other parts of the conference. Because there are so many presentations, and this is an e-newsletter, I offer you a brief introduction — and then give you the presenter himself or herself. I hope you find this useful.

Thursday

Fundraising Workshop

The Fundraising Workshop offered participants with a wealth of experience, exciting ideas and advice.

Presentations from:

Marianne Naafs-Wilstra, VOKK, Holland

Marianne talked of how survivors, their siblings and families generated significant income, but also achieved many life goals too through a major challenge — a 9-day cycle ride covering 600 km.

Jakob Vibild, FMKB – Denmark

Jakob talked to us about Kemo Kasper, a computer generated “super hero” who goes to battle against cancer. This computer game offers the opportunity not only to raise money but to educate too.

W Cui, Guangzhou Childhood Cancer Parents Group

The Magic Bean has not only raised money and awareness of childhood cancer in Guangzhou, but has also been a great way to build a strong relationship between the Childhood Cancer Parents Group and the hospital.

Ann-Mari Hellman and Ylva Andersson, Barncancer Fonden, Sweden

Barncancer Fonden were able to show how product development can act as a motivator to young people, a fund raiser and an awareness raiser. Nearly 20,000 HOPE necklaces had been sold by the time of the conference raising nearly 300,000 Euros.

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L Alejandre, AMANC, Mexico

Showed the power of the parents group raising awareness and building relationships. Their activity over the last six years has helped change the way the Mexican Government supports children with cancer.

R S Soepardji, Yayasan Onkologi Anak, Indonesia

Showed how the Childhood Cancer Foundation raises money through events and individual donations to help children with cancer from poor families in Indonesia.

C Wandzura, Kids Cancer Care Foundation of Alberta, Canada

Christine gave a workshop on how to run a special event. It was full of ideas and tips to help you on your way, and good advice to avoid the pitfalls.

After a packed full afternoon, we enjoyed the traditional "Meet and Greet" evening where parents, survivors, and care workers joined together to get to know one another and to understand the impact of cancer in their country. Wonderfully organised by our host organisation and under the watchful eye of Gerlind Bode, each delegate brought food from their country and we were all offered a huge feast of different flavours and tastes.

Friday

R Arceci, Sidney Kimmel Comprehensive Cancer Centre at John Hopkins, USA

Giving a keynote address, Bob Arceci was an exciting presenter. In his presentation — New Horizons in Paediatric Oncology — he took us through quite a bit of history and showed us how the science had developed. He also looked to the future and gave us his views on where science can and will go in the future. He spoke about targeted therapy and the impact of the genome studies. But most importantly, he felt that what was very important was to be global about our approach. And that all work done in this area needed to benefit all children with cancer across the globe.

Friday late morning provided us all a great opportunity to hear about survivor issues and the treatment of young people.

Dorothee Schmid, a survivor and psychologist, Germany

Dorothee gave an excellent presentation highlighting the key issues for patients and survivors. She highlighted the need for effective information both for patients, but also for the general public — providing better general awareness. She wanted the myths to be dispelled around cancer and childhood cancer and what survivors can achieve. She also focused on follow-up and aftercare and shared the areas that were important to survivors.

Carole Easton, CLIC Sargent, UK

Carole talked about the work CLIC Sargent is doing with the UK Government, called the National Cancer Survivorship Initiative. As part of the initiative, CLIC Sargent is building up a full picture of what young people want and need and what their issues are, which she shared with us. She finished the presentation off with a DVD, which can be viewed at www.clicsargent.org.uk.

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Dr D Christina Stefan, South Africa

Shared her research work that she has been doing in South Africa amongst adolescents with cancer. She highlighted the need to listen to young people, to ensure that there are effective transitions from child to youth to adult support.

Friday afternoon was filled with a range of presentations sharing different areas of research from around the world. They included:

M Sitaresmi, Indonesia

In her research investigating the health-related quality of life assessment in Indonesian Childhood ALL, she aimed to assess the health related quality of life and also to understand the influence of demographic and medical characteristics. Her research showed that parents tended to be more anxious than the children themselves, and she also found much fear and emotional stress, due to dissatisfaction with the medical support provided and the fear of the procedures. In a place where there is nearly 26% abandonment, her research showed a significant need to support the psycho-social needs of the patient and carer was vital.

Dr Rachna Seth, AIIMS, India

In her research into survivors, Dr Seth demonstrated the medical and education effect of cancer on children in India, which she has studied from the survivor clinic. She also showed that not only is there a significant difference between the numbers of boys to girls who get treatment but also who come back for follow up support. The other challenge that she said is faced is how to share the information to both the parent and the child so as not to risk them not returning for on-going support.

E. Hoven, Karolinska Institutet, Sweden

Looking at adult survivors of Childhood CNS Tumours, she reviewed the persistent health care needs and long-term impact on the family. Her findings included that the greater the disability, the greater the needs of the family both psychologically and from a health perspective. She also saw a link between unmet needs and lower levels of education.

A. Borgmann-Staudt, Charite Campus Vichow Klinikum, Berlin University, Germany

In her study of fertility after chemotherapy and radiotherapy, Ms Borgmann-Staudt highlighted the reasons why infertility was experienced. But she also highlighted that there was also a significantly lower level of desire to have children by young people who had survived cancer. Two common reasons for this were fear that their child would have cancer too, and fear that their cancer would come back.

S Gottschling, University Children's Hospital Homburg, Germany

This presentation took us on a journey through the use of complementary and alternative medicine in paediatric oncology, highlighting the potential benefits of complementary therapy. The challenge is that there is limited research to support some of the claims.

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Saturday

On Saturday, we all came together as a Child Cancer Community — nearly 2000 doctors, scientists, nurses, parents and carers and survivors — to hear Prof Alan Craft, Head of Child Health within the School of Clinical Medical Sciences, University of Newcastle upon Tyne, talk about paediatric oncology — the past and the future. He took his audience through the amazing developments over the last centuries, and in his views of the future, he highlighted the importance of the international perspective and the need for global studies and trials. He also highlighted the important work that SIOP has done to help share knowledge, information, and education across the world.

Alan Craft also praised the work of Tom Voute, a founder member of SIOP 40 years before, who died a month before this year's conference.

In summary of his perspective on the future advances, he talked about screening, prevention, earlier diagnoses, and new methods of treatment — like targeted therapies. He also outlined what he thought the barriers were to development — the lack of interest by pharmaceuticals, the difficulties of setting up clinical trials and building that better understanding worldwide.

On returning to the Parents' Conference, we were once again presented with a wide range of speakers who focused on the importance of data collection and registries. Gerlind Bode has written an article about the German Childhood Cancer Registries following Peter Kaatsch's talk. Other speakers included:

I Soelistyo, Indonesian Care for Cancer Kids Foundation

Ira gave us an interesting presentation on how the parent organisation took a role in helping the hospitals in Indonesia set up the childhood cancer registry. In an environment where everything was paper based, and there was no person taking responsibility to manage records, there was limited success in growing a useful database. However, with the support of the Parents' Foundation, hospitals systems have been computerised and there is now a strategy to deliver a national cancer registry.

Olle Bjork, Barncancer Fonden

Shared with us the development of the Swedish Cancer Registry, which began in 1980.

Peter Kaatsch — Germany Registries

Please see Gerlind's article on page 4.

Saturday afternoon started with a celebratory but very sad moment. Gerlind Bode, Marianne Naafs and Benson Pau of ICCCPO shared their memories of Geoff Thaxter, ICCCPO's Chair until his untimely death in August last year. Geoff had been very active with ICCCPO for the last 10 years and Vice Chair since 2003. His wife, Gill and their daughter, Becky, were in the hall in Berlin to share the memories with their friends and fellow colleagues. There is an article later in the newsletter about Geoff and the amazing work he did both in the UK and internationally. The child cancer movement misses him deeply. We had another opportunity to remember Geoff when Christine Wandzura presented to the whole conference the "Through my Eyes" project, a photography project presenting

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how patients feel about cancer, their care, and life. It presented a strong focal point for International Childhood Cancer Day in February each year, giving every country the same theme to work on which provided a stronger focus for international awareness.

What has happened in 2008?

Benson, ICCCP's acting Chair, led the ICCCP Board in sharing with delegates the wide range of activities that the ICCCP Board have been supporting around the world:

- Irina Ban from NURDOR talked of her work with EURODIS, which is a pan-European patient organisation for people with rare diseases. In a meeting in Barcelona, earlier in 2008, 17 European countries were represented along with ICCCP. The main focus was learning about how clinical trials could be set up and the importance of them.

EURODIS has also drawn together the FDA, pharmaceuticals and parent organisations in a round table discussion on orphan drug development. This is the beginning of some important work.

- Julian Cutland shared information about the meeting and workshop they held in April in Johannesburg, which launched the ICCCP Handbook. 8 different African countries were represented, including Nigeria and Zimbabwe. It provided much information and also provided much food for thought. It is very hopeful that children throughout Africa will gain from this knowledge sharing.
- Other meetings had been run in Muscat, Oman, Russia and Macedonia. And there is planned a meeting in Beirut. This is ensuring that information and support is being shared across many countries.

- In June, 16 countries gathered together at a meeting in Quito more than 80 people representing 48 organisations! This was a first for Latin America and augurs well for the conference in São Paulo.
- In Canada and North America there has been a big drive to recruit more members. This will provide a greater pool of information and best practice to share.
- In Oceania, through lobbying from the parents groups and others, New Zealand has provided funding for three years to support children with cancer in the Pacific islands. Previously there haven't been any services available. And last year, the Tonga Child Cancer Foundation was set up. Plans for the future include setting up a Centre of Excellence in Fiji.

In the conference interactive session, there were many subjects discussed and they included:

- 2009 marks ICCCP's 15th Anniversary, and a special book is going to be produced to show the success story. For more information about this, contact the secretariat.
- The Through my Eyes project was a great way to provide focus for International Childhood Cancer Day. It was felt that there needed to be a theme and a hook to develop the stories from. For further information, contact Christine Wandzura.
- Members discussed the need to ensure continuity of ICCCP, and there was a call for more Board Members and regional representatives in future years. It is vital to ensure that people with energy, vision and passion engage with the organisation. Not only does ICCCP offer a place to share knowledge, information

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and best practice, but it also offers the base for world wide advocacy. Through the Survivors Group, ICCCPPO and SIOP, you have the therapeutic alliance. It was important to work together to lobby the political and medical bodies throughout the world, like the UICC and WHO.

- The work of World Child Cancer Foundation was shared with members. WCCF is the fundraising arm to ICCCPPO. It's objective is to help make a reality the WHO declaration that all children should have right to access optimal treatment. Through funding from business people and major donors, WCCF will fund projects in developing countries to provide support and relief to families across the world. Two projects have already been started. A project in Malawi and one in Colombia will be the flagship projects for the WCCF. For more information, look at the website at www.wccf.org
- The articles of confederation were amended to allow board members to have a 3 year term for 3 years, and the chair having 4 terms. It also allowed for

a small number of board members to become advisors. This is part of ICCCPPO's strategy for ensuring continuity into the future.

- It was announced that the ICCCPPO website was to be redesigned and launched in 2009. Julian Cutland, who has been managing the website since 2001, was thanked for the huge amount of work that this involved. The new website would take account of new design and technology and was being created at no cost to the organisation.
- The 2009 conference programme was being produced and there was a request for abstracts. There was also a call to members to attend the conference in São Paulo to support families in Latin America. As part of the conference discussion, there was a debate about the info-market and its future. More information on the conference is available from Anders Wollmën and Anita Kienesberger.

Sunday

The conference continued to offer a wealth of presentations of best practice, activities and research. They included:

Marianne Naafs-Wilstra, VOKK, Holland

Shared a structured reward system for children with cancer, in the shape of the bravery beads programme. By using beads as a reward, they were able to provide a point of understanding of what the child is going through; they created a bond; and they stimulated communication.

Shambhu Prasad Kadariya, Cancer Society Nepal

Shared with the conference the Nepalese perspective. In such a rural landscape, families with children with cancer face isolation, lack of support and services, and inability to pay. The Cancer Society Nepal try to raise awareness, support patients and their families with psychosocial and financial support, and establish palliative care centres.

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J Lamont, Candlelighters, Ottawa, Canada

Shared one of their programmes using art and art therapy to support siblings of children and young people with cancer. Not only does it give them an outing and attention for them, but using art, they are able to draw out some of their emotions and issues enabling greater communication.

In addition to the parents' conference, the survivors group had their own programme. For presentations from that part of the conference, please contact Prudence Walker-Cuttance on iccsnetwork@gmail.com

Below are presentations from the Nurses conference, where many different research projects were shared.

Presentations from the Nurses conference

Living with childhood cancer — family members' experiences and needs

Maria Bjork

Maria discussed a study on how cancer and its treatment affect family members. They observed and interviewed 17 families, noting parents' and siblings' swings between insecurity, worry, gratitude and optimism, and showed how a good relationship with staff can help families. The enthusiastic audience asked questions afterwards.

Cancer childhoods: analysis of data from an ethnographic study of childhood cancer in British Bangladeshi children

Paula Kelly

Paula talked about her investigation into the impact of cancer on British Bangladeshi children living in the UK, including economic effects, relationships with parents, child rights and cultural behaviour. She advocated normalisation strategies, although her study showed that children tend to resist adults trying to implement these strategies.

Struggling on: experiences of foreign-born parents in childhood cancer care in Sweden

Pernilla Pergert

In a lively talk and question and answer session, Pernilla described the powerlessness felt by Sweden's foreign-born parents when struggling to get the best health care for their children. Health care staff need to be more aware of problems and bridge the obstacles to create trustful co-operation in the fight against childhood cancer.

The experience of families with children who've received a haematopoietic stem cells transplant (HSCT)

Marie-France Vachon

Marie-France explained that HSCT (bone marrow transplant) can be a very stressful experience for a child and their family, including the sibling donor. She believes it's important to normalise the treatment, making it a day like any other — although the children's biggest problem tends to be boredom — and to get fathers more involved.

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The process of relinquishing — the parental struggle between loss and preservation of their child receiving palliative care

Marijke Kars

Parents play the most important role in supporting a dying child, but at the same time they have to deal with their own grief. They have to try to make the most of the time they have with their child, while being aware of their inevitable death and the need to let go. It was great to see so many of the audience responding to this emotive subject.

Evaluating support groups for brothers and sisters of children with cancer

Margaretha Nolbris

A very interesting talk about the feelings of siblings and how we can help them to express the m, through painting or by sharing their experiences with a peer group. The 8-18 year olds studied found the group a therapeutic way to listen, recognise similar experiences, find inner strength and build their own identity.

Implementing a pain protocol in a paediatric haematology and oncology ward

Jaklien Bistoën

A Belgian team in Ghent University Hospital is using a holistic approach to pain management through better communication, improved knowledge, accurate pain assessment and standard treatment plans. The very well-informed audience were most appreciative of this detailed presentation.

An appreciative inquiry approach to paediatric oncology nurse education at the University Children's Hospital, Belgrade

Jelena Lazic

Jelena works at the oldest children's hospital in the Balkans. She explained that hospital staff had become aware of a lack of systematic clinical education, and decided to

devise an education programme. Nurses are now more self-confident and self-sustaining, without compromising their dedication to their patients.

An appreciative inquiry approach to practice improvement in clinical care

Karin Orgulas

Tallinn Children's Hospital wanted to improve nursing education and identify the core values of positive change partnership. They also needed to optimise resources in a small oncology unit, so they decided to create a programme based on patient information about diseases, chemotherapy and potential complications.

The importance of a standardised telephone triage practice by nursing staff and doctors in a paediatric oncology unit

Panteleimon Perdikaris

Panteleimon works at a hospital in Athens where there is no standardised telephone triage practice, so all the parents' calls, day or night, were being diverted to the physician in charge. They have now started a project to involve the nursing staff more, improve the quality of information, reduce unnecessary calls and identify FAQs.

Collaboration between doctors and nurses in providing information to patients and their families

Goda Vaitkeviciene

Goda's hospital in Vilnius, Lithuania, found that cancer patients' families were sometimes complaining of a lack of information. It was agreed that more communication between nurses and doctors would help. Now they hold regular meetings where nurses and doctors are equal partners in the discussions. A very informative presentation.

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Multidisciplinary support for professionals working in paediatric oncology

David Hobin

Another appreciative inquiry! This one was used to develop a support mechanism so that staff at the Birmingham Children's Hospital Oncology/Haematoiology Unit could discuss and explore challenging issues related to their work. They hope this will reduce stress and conflict for the workforce and improve cross-discipline working.

Telephonic advice to patients and parents by paediatric oncology nursing staff: identifying areas for improvement A FECS (Federation of Europe Cancer Society) project

Marjolein Lakerveld

An enthusiastic audience welcomed this talk on just one part of a massive 2-year project involving 15 teams from all over Europe. The Emma Children's Hospital in Amsterdam audited and assessed their clinic telephone line to standardise and document the information given to parents of children with cancer.

Symptom assessment with patient surveys

Christina Baggott

The University of California compared the symptoms declared by patients in a questionnaire with the symptoms reported by their clinicians. I wasn't surprised to hear that the patients wrote down much more than the clinicians reported, and there were large discrepancies in the assessments for nausea, vomiting and diarrhoea.

Strategies to reduce central venous catheter (CVC)-related bloodstream infections (BSIS) in paediatric oncology patients

Rita Secola

Very informative! I learned that CVCs are in-dwelling catheters for patients who need multiple deliveries of medications

and therapies. Unfortunately they are quite risky, with BSIS mortality rates of 1225%. Research is now being carried out to find out whether staffing levels or patient acuity can help reduce these mortality rates.

Enteral nutrition during blood and marrow transplantation

Ellen Olson

The Children's Healthcare of Atlanta carried out a study to find out whether enteral feedings can work for paediatric BMT (blood and marrow transplant) patients. They studied 31 paediatric BMT patients with anorexia or inadequate calorie intake, and discovered that enteral feedings do work and have advantages over TPN.

Pilot study into low level laser therapy (LLLT) in the treatment of oral mucositis on a paediatric haematology/oncology ward

Veronique Van de Velde

Children often suffer severe oral mucositis during induction therapy for ALL or after high-dose chemo. This pilot survey showed that LLLT, used with standard oral care, had an immediate analgesic effect, improving patient comfort and healing lesions. The audience reacted enthusiastically to this very positive presentation.

Post-operative nausea and vomiting (PONV) in children with brain tumours: care at the beginning of the continuum

Susan Neufeld

Susan reminded us that the successful management of PONY is vital to the recovery of children after surgery. It causes discomfort and distress, increases cranial pressure, and can actually delay recovery. However, the incidence of PONY is not high enough to warrant aggressive prevention and treatment strategies.

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The benefits of working together: a collaborative approach to standardising care for paediatric oncology patients in NSW

Dianne Cotterell

An inspiring presentation about people working together successfully. Staff from 3 hospitals in New South Wales have been collaborating for 9 months. They've improved their professional relationships and nursing care, reconnected with their share-care partners, and created a voice for paediatric oncology nursing in the adult cancer world.

Developing nursing care guidelines for children with cancer and their families

Masayo Uchida

Another very informative talk. In Japan, nursing care for children with cancer presents problems, as many nurses have limited experience in this kind of care and there are no benchmarks to guide them. Masayo told us how they are developing guidelines to help nurses throughout the cancer journey, from initial communications onward.

Nutrition in paediatric oncology units in the UK and Ireland — a survey of practice

Karen Selwood

I was surprised to hear that there isn't a consistent approach to nutritional support, education or assessment for children with cancer in the UK and Ireland. This was proved by the results of a questionnaire sent to 21 paediatric oncology centres, sent to nursing staff and dieticians. 100% of the nurses responded and 66% of the dieticians.

Focus on nutrition by a nursing working group from Central America: 1 year follow-up

Terezie Mosby

Terezie told us very movingly that in Central America, primary and secondary malnutrition

are common among children with cancer. This can be caused by financial problems, understaffed hospitals, poor communication with kitchen staff, and a lack of nutritional standards. A few significant changes have been made, and more are planned.

Reaching a national consensus on an approach to low risk febrile neutropenia: the challenges of a Delphi survey

Faith Gibson

Febrile neutropenia is the second most common reason for admission to children's oncology wards, but there is widespread variation in practice throughout the UK. Even the definitions of 'fever' and 'neutropenia' differ. Faith explained how guidelines are now being developed and unified thanks to the results of a Delphi survey.

A pilot program to follow up adult survivors of childhood cancer in British Columbia, Canada

Grace Chan

The program evaluated the health status of survivors who were at highest risk for late effects of treatment. However, only 19% of former patients accepted the invitation to participate. New health problems were detected in 50% of these respondents — but 100% of them found the visit useful and informative.

Innovative role development for paediatric oncology nurses

Jeni Moodie

An audience of many different nationalities responded positively to this presentation on how the Children's Cancer Centre in Australia trains nurses to be CNCs (Clinical Nurse Coordinators). CNCs provide expertise in coordination, education and research, to ensure optimum care. Future aims for these nurses include developing mentoring skills.

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Five years of nurse practitioners in paediatric oncology (NPPOs): what has been achieved?

Corry van den Hoed-Heerschop

Since September 2004, the Erasmus MC-Sophia Hospital in Rotterdam has employed 3 NPPOs to coordinate, structure and standardise the care of children with ALL. During that time their role has evolved, and in future their functions will grow to include prescribing medication and caring for other oncological groups.

Improving quality, reducing risk and increasing safety in the paediatric oncology setting

Patti Byron

Many factors can affect patient safety, so it's essential to reduce risks and mistakes to an absolute minimum. At the British Columbia Children's Hospital, they have created a new role of Quality and Safety Leader, who works with oncology program and hospital leaders to identify and reduce risks. A very thought-provoking presentation.

The conference was a huge groundswell of views, opinion, good practice and support. Parents who were there for the first time all commented on how it had encouraged them not just with many good ideas to put into practice, but also with renewed vigour to make a difference, knowing that there was a worldwide network of support behind them.

São Paulo 2009

The conference in 2009 is in São Paulo, from 5th – 9th October. Please see the newsletter and website for more information.

Conference Committee

Anders Wollmén, Chair, ICCPO Parent's Program Vice Chair, anders.wollmen@bredband.net

Anita Kienesberger, ICCPO Parent's Program, dachverband@kinderkrebshilfe.at

Prudence Walker-Cuttance, Chair, ICCPO Survivor's Program, iccsnetwork@gmail.com

Gerlind Bode, Local Organizing Committee, gerlind-bode@t-online.de