

ICCCPO Newsletter

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por favore porganse
en contacto con la
Secretaría de ICCCPO
en Hollanda.

Some words from the editors ...



Dan Mornar (right) at Meet & Greet

Those who attended the annual congress in Vancouver will agree with us: it was an excellent meeting, with a record of attendants and a record of countries present. Thanks to the donations from members to the Parents helping Parents Fund and sponsoring of the conference by Clic Sargent and the Lance Armstrong Foundation we were able to provide scholarships to many representatives from parent organisations and survivors' groups. This

Newsletter offers a variety of articles about and from the conference and we hope to publish some more in our next number. Survivors have a special place in this newsletter as they had at the conference. Unfortunately we cannot share with you the beautiful play that Dan Mornar and his survivors' group had prepared for the Meet & Greet.

Elections for the Executive Committee were held and Anita Kienesberger from the Austrian parent organisation and Benson Pau from the Hong Kong parent group were elected to the board.

Mark Chesler and I (Marianne Naafs) will not disappear; we have committed ourselves to several tasks, like so many of our predecessors have done. After all, the work has to be done by all of us together.

ICCCPO is still growing in numbers and now has 81 members from 58 countries. Membership is not our main goal, our confederation is all about sharing and working for better chances and a future for children with cancer worldwide. Therefore ICCCPO is collaborating more and more with the doctors through SIOP (international and continental) and with organizations such as UICC, WHO etc. We cannot change the world in a day, but one can move a mountain by moving it shovel by shovel.

We hope that all our members will participate in the next ICCD on February 15, 2006, and will contribute to the continuation of the Through My Eyes Project, which was a great launch at the Vancouver conference.

And of course we wish you a successful year!

Marianne Naafs
Gerlind Bode



Meet & Greet

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ICCCPO launches three new programs at the Vancouver Meeting



The ICCCPO introduced three new exciting projects during this year's SIOP/ICCCPO conference. The first program was the Developing Countries Working Dinner. This evening was a three-hour working dinner that explored important issues and needs of groups from countries that do not benefit from state-of-the-art treatment and care. The outcomes from this evening have now been circulated to the participants and our hope is that it will have a lasting impact on the programs provided by the participants from over 20 developing countries.

Also featured for the first time was the Pre Education Day Workshops. Topics included fundraising, volunteer management, program evaluation and marketing and were delivered in an interactive, insightful and informative workshop format. It is this kind of information that children's cancer agencies from around the world come to learn from at these forums.

Delegates from parents' groups then took part in four full days of conferencing and networking including a social program, which included the very popular Meet & Greet which featured food and beverages supplied by the participants and the ICCCPO annual dinner.

Perhaps the highlight of the conference for all the participants was the launch of a three-year project entitled: "Through My Eyes" A Day in the Life of Children with Cancer Around the World. This first ever international photo exhibition, sponsored by Roche, was organized and managed by the Kids Cancer Care Foundation of Alberta and featured photos taken by children in 91 cancer clinics from 33 countries. Conference attendees were provided a glimpse of what childhood cancer looks like in other countries through this impressive exhibition.



Next year, the theme will be childhood cancer in the classroom and more details of the project will be sent out to all SIOP members early in the New Year. This exhibition is an important way of giving children with cancer a voice to tell their stories! For more information you may contact:

throughmyeyes@kidscancercare.ab.ca

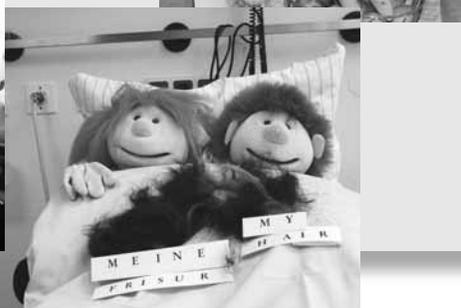
Chris Wandzura, ICCCPO-Board (Secretary)

ICCCPO - news



"Through My Eyes"

A Day in the Life of Children with Cancer Around the World



ICCD – 2005

The International Childhood Cancer Day on 15th February was observed by a growing number of ICCCPO members. This year the main theme was the programme "Through My Eyes" which encouraged children to take photographs of what childhood cancer meant to them on that particular day.

As well as "Through My Eyes" members celebrated the day with a range of events. In **Mexico**, the ICCD took place at Los Pinos, the official residence for the Presidents. This year, the First Lady provided a reunion of more than 500 people at their residence. Three young survivors talked to the media.

In **India**, Sahayta organised a painting competition and distributed gifts to children and survivors. Also in India, one of the CanKids events was a day at an amusement park where children were able to release prayer boxes attached to helium balloons.

In the **UK** a poster campaign was used in hospitals to encourage children to take part in "Through My Eyes". An international edition of Contact magazine was produced and distributed to celebrate ICCD.

In **New Zealand** there was media and radio coverage with an on-line auction of donated items.



In The **Netherlands** there was a survivors conference, a drawing competition and "Send a Card" where children were invited to send a card to other children in Eastern Europe.

In **Iran**, MAHAK supports over 5,000 children through its outreach programs and produced yet another wonderful poster.

In **Singapore**, gold ribbons were distributed to raise funds and awareness. In Russia, CAPAC took 140 out patient children to a restaurant and held three parties in the hospitals. In the **Ukraine**, the member Viden organised media coverage and a tea party for children in hospital.

In **Serbia**, there was good media coverage and posters produced. In South Africa, there was a sponsored golf day to raise funds, a party for 250 children, and visits to 19 schools to raise awareness.

In **Bangladesh**, CLASS organised the distribution of medicines and gifts, and a rally supported by 500 school children.

This year, the event was supported by José Carreras who has his own international Leukaemia Foundation.

*Geoff Thaxter
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From difficulties to solutions for the rare disease community

From June 21 through 22, 2005 the Government of Luxembourg supported with the participation of the European Commission a conference of EURORDIS on the topic of rare diseases. EURORDIS is the European Organization for Rare Diseases. It is a patient-driven alliance of patient organizations and individuals active in the field of rare diseases.

The conference covered a wide variety of problems connected to those diseases which are relatively unknown as they occur only very seldom. Though cancers in childhood is also rare – when compared to the incidence in adulthood – it occurs much more frequently than a whole number of genetic disorders. Thus, a great number of problems unique to the group of rare diseases are in many countries of the European Union already solved in the field of pediatric oncology, such as registries and cooperative treatment protocols.

However, there is still the problem of the orphan drugs. Many medicines applied in treating malignant disease in children are not approved for the use in children, though used successfully over many years. And this is a common goal to fight together with all the other self help groups, who gathered in this meeting with the aim of better care for people living with rare diseases.



G.B.

The Listening to Children and Young People with Cancer Project

The 'Listening to Children and Young People with Cancer' project was set up through the support of Macmillan Cancer Relief to explore the perceptions of children and young people with cancer regarding their care and support needs. Thirty-eight children and young people aged 4 to 19 years took part in the project. They were either still on treatment (20), at the end of treatment (9) or had finished treatment 6 to 18 months ago (9). Creative, age appropriate, data collection techniques were used to enable the children and young people to talk about their experiences and give their views of care. The play specialist on the research team used 'Tweenie' dolls or other soft toys as puppets to talk with the 4 and 5 year old children. The use of familiar objects was thought useful to help the researcher to enter the world of the child. The 'draw and write technique' was used with those 6 to 12 years old. This involved prompting the child to do a drawing at the start of the interview, followed by questions about the child's experiences. The wording of the prompt and the subsequent questions was adapted according to the stage of the cancer journey the child was at. An activities day was carried out with young people 13 to 15 years old, during which the young people interviewed each other about their experiences and took part in a focus group. Other young people were interviewed individually. The data were analysed and themes pulled out; some of the key points from the findings are presented here.

Regarding the hospital environment, the children and young people wanted the hospital to be bright, colourful, comfortable and non clinical. The older children said that they would like separate areas for young children as they found hearing them crying distressing and noisy. Toys, the playroom and activities were clearly essential features of hospital across the age groups as they provided distraction and prevented boredom, 'when we go to hospital it could be five minutes or five hours so having something to do is really important, having the right things' (Kate, 10 years old). The drawing below by Holly, 9 years old, shows a child who is 'happy because she has things to do'. The young children spoke a lot about the toys and playrooms at the hospitals they had been to and also about activities they had enjoyed with play staff. It was important that toys and activities were easily accessible and always available. Some children spoke about staying in bed all day having treatment and when they were able to get out of bed the playroom was locked and the play staff had gone home. It was important that there were age appropriate toys and activities available, many of the older children felt that everything was aimed at young children. The young people spoke about being 'pestered' to take part in activities and said that when they were unwell they often preferred their

own space and just watch a film or read, 'I wasn't into all this like let's do gluing and sticking and stuff' (Louise, 17 years old).

The role of family, friends and hospital staff featured prominently in the children and young people's stories. These people provided support and helped them through the 'hard times'. It was important to all of the children and the majority of the young people that their parents were able to stay with them, 'didn't like being on my own in a room, it was scary when Mummy had to go' (Lisa, 6 years old). Many of the children spoke about missing their siblings whilst they were in hospital. The young people spoke about support from their friends, however it was difficult to keep in touch with them during hospital admissions. Nurses were described as 'kind', 'fun' and 'helpful' and played a particularly important role. The participants appreciated it when staff took the time to get to know them and 'chatted' about their life outside hospital. For the young people, nurses chatting to them helped them to pass the time whilst they were in hospital and some said that they looked forward to seeing the nurses. Many of the children wanted the nurses to play with them but they were perceived as often being too busy. It was important that nurses were reliable, a few children spoke about nurses promising to come back to see them and later realising that they had gone home.

The following account from Jack, a 12 year old boy who had acute lymphoblastic leukaemia and finished his treatment 4 months ago, demonstrates the importance of information and how some children want to be spoken to directly by hospital staff. Lack of information made many of the children interviewed worry that the changes they were experiencing would be permanent.

It was really important to Jack that hospital staff spoke to him directly and in an age appropriate manner, 'I had to have a scan but they didn't tell me what it would be like. Nurses and doctors don't tell you enough, they treat children different. When Mum is sick and has to go to the doctors they treat her different...They use posher words but they are words I can understand, they could use them with me'. Jack wished he had been given more information about treatment and side effects, 'They tell you the medicine will make you better but they don't tell you how it works'. He thought it was particularly important that children are given information about steroids, 'I couldn't stop eating. I was worried I was always going to eat like that....I got really fat and I was worried I would stay like that. I think they should warn people about that'. Jack spoke about having treatment and his worries, 'I got a really sore mouth and had to go to hospital and I got tonsillitis and I was

worried and I thought after all this, why me? I was worried, it was scary, I thought I would not get better'

The older children and young people described what it was like having treatment and how it made them feel, 'it made me feel so awful and sick and just like the kind of ill that I just didn't even think anyone could feel...I never felt so disgusting in my whole life' (Louise, 17 years old). Needles were something which lots of the children found very stressful and worried about having. Many of the children and young people spoke about how the cancer and treatment placed limitations upon their lives. Being in hospital and attached to a drip took away their freedom and they often felt too tired and sick to do things, 'sometimes I don't feel like playing anything' (Amy, 4 years old).

This study provides an insight into children and young people's experiences of cancer care services and highlights the aspects of care that are important to them.

Many of the findings have implications for the development of services, which are child-oriented and meet the needs of children and young people with cancer.

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The ICCCPO Conference in Vancouver: A Survivor's Perspective

First of all, I am deeply grateful to the Indonesian Childhood Cancer Foundation (ICCF) which has given me a great opportunity to attend this conference. The foundation, which was founded in 1993 by several groups of parents whose children were afflicted with cancer, one of whom is my mother, has put a great deal of emphasis on the people who have got cancer and their parents. Supported by local and internationally proficient doctors and several international organizations (e.g. SIOP, ICCCPO, ESO), ICCF has become the front line of childhood cancer prevention in Indonesia. As a survivor, I am greatly honored to participate in all ICCF's activities to come.



The newly elected board of the survivors' group

I didn't expect much on this conference at first, but what I got was a whole lot more than I ever expected.

It started off casually. I was introduced to a lot of people. Doctors, parents, survivors, etc. Then, the conference began and I was supposed to be very active in it. But, they talked about things I did not know well enough to be with them. For that, I could only blame myself. So, I just listened and listened. My late father once said, "a good speaker is a good listener." And boy, he was right. Not only had I got a good impression by then, but also, I've learned so much about things concerning childhood cancer and the struggle behind it from many different perspectives (countries, either developed or developing).

The next day, I met survivors from all over the world. (Serbia-Montenegro, Philippines, Armenia, Sweden, Japan, New Zealand, Korea, Hongkong, Austria, Germany, Sweden, Netherlands, Romania, Russia, and of course, Canada.)

I must say, it's kind of regretful that I didn't have enough time to get to know all of them, hear all of their stories. However, I did hear some of them and when it comes to comparing stories about when they had cancer and how they managed to overcome it, it was never a dull moment.

One of the Canadian survivors, Robyn St. Amand, told me that he had to go through a vicious chemotherapy that literally was able to kill him. He was very skinny, like a skeleton and parts of the skin on his face were badly damaged. Plus, he has had a rough time with his parents who were getting a divorce so he had to



Survivors from Vancouver presenting

stay with his grandparents. Hearing such a story really makes me feel that I was living in a Disneyland back then. However, there are no happy stories when cancer is involved. He was surprised to hear that I had to go through bone-marrow tests for two years every month. He admitted he only went through that horrible test once. Lucky bastard!

Then came the election of the new executive committee of the survivors' group. Some of the survivors protested about one of the criteria, i.e ; the candidates should have attended this meeting at least once. One of the protesters was James Auste, a survivor from the Philippines. He has been very actively involved with his cancer organization in his country for a long time (which makes me embarrassed, so to speak) and he thinks, along with some of us, that it is unfair to have this kind of criteria, considering many of the developing countries had great difficulties in bringing their survivors to this conference in the first place. Finally, the criteria was omitted, replaced by allowing any survivors who have any experience working with the cancer organizations to be eligible to become members of the committee.

Six candidates did some great presentations. However, only three new executive members were selected. One from India, another from Serbia-Montenegro and the other from Canada. I was very excited by these new members because those are the candidates I voted for.

The sessions we had were beyond my expectations. I thought we were going to have some boring lectures, but instead, we were doing interactive activities, like role-playing, creating presentations in groups, and group discussions.

For the mentoring session, we were divided into several groups. Each group was given a study case with

a problem concerning mentoring. We were told to do some kind of role-playing also and how to solve the problem. It was great fun and we had a super time.

For the "How to be an Organizer session", we were again divided into groups. Each group should choose a topic and prepare a presentation in front of everybody. The topic included Advocacy, Mentoring, Fundraising, and Developing International Network. A good question about whether or not those presentations are applicable in the real world was raised, which resulted in great ideas, yet simple presentations. For example, for the fundraising topic, the group suggested creating some designed postcards that can be sent through the internet, so that everybody all over the world can sell them. It's a marvellous idea because it is so simple and can be done easily.

For the "Creating a Volunteer Base" session, we were divided once again into groups. We were asked to discuss about how to use volunteers in raising funds. In our group, we organized some kind of running event. We discussed it a lot and I was kind of surprised that one of the survivors had done this kind of event before and it involved 45,000 people. They all did it for charity. I asked why they became volunteers. They said they just did it as it made them feel good about themselves, that they were doing all this for charity. It is a culture thing and I feel glad we also have that sort of thing in my country, although we haven't managed to stimulate 45,000 people to do things for charity in one event.

Another session that was unforgettable was the "Meet and Greet". We had tons and tons of food from various countries. This is where we were mingling among a lot of people, getting to know them. It was fun. One of the survivors from Germany told me about her survivors' group activities. They built some sort of exclusive camp for the kids with cancer so that they can have fun together (see German Presentation). It seems that camping for children is a cultural thing . I wonder if it also can be applied to children in my country.

A great show was performed at the "Meet and Greet". The performance was done by all the Canadian survivors. All in all, it was a wonderful night. We got home quite





late, hit a Japanese restaurant first and went straight to bed.

The farewell night was also unforgettable. It was called Dinner Cruise. We were taken by a big boat and travelled around Vancouver (which is basically an island connected by bridges). We had dinner (which was absolutely magnificent), had some drinks (one of the Canadian survivors suggested I had a Honey Logger, which is a kind of beer. It tasted great,

especially in this cold weather), and had some dances. I didn't do any of that, of course, that would be embarrassing. I just watched.

I also got to know some survivors from Japan and Korea. Their English was not so good, but somehow, we managed to tell each other our stories. One of the Japanese survivors had to go to Canada for medical

treatment, because they do not have the proper equipment. I was quite surprised about this, as I thought that Japan is one of the most developed countries. But that is the fact.

The next day, the Canadian survivors had another unforgettable event for us. A CASINO NIGHT! Yes, we were given some fake money and we could spend it on the games available there, like poker, roulette, black jack, etc. After that, we could exchange the money we had left for souvenirs. It was an extremely great night. We were having a blast and also we were bonding. I met an Armenian survivor and he told me that in his country, people with cancer or survivors do not have to pay for their own medical treatment. I was kind of stunned. I wonder when we are going to be able to do that.

One thing that I got from this conference, or, as I prefer to call it, adventure, is that my eyes are wide open now. Meeting with so many survivors from other countries is truly inspiring. Things that they have done for kids with cancer are really driving me to do something similar here. Now that I've got the knowledge, the experience and the ambition, I finally can do some of that soon, too.

Priesnanda Dwisatria, Indonesia

Necessity of Support for Young Adult Survivors*



Issues for life, love and happiness get more complicated for a young adult who has survived cancer. Once a childhood cancer patient becomes an adult they fall into a dark gap with very little support. Just as children, young adults should be given the opportunity to explore potentials and search for their identity.

Support is a fundamental part of the healing process which allows for mental and emotional wounds to heal.

As we leave high school and pursue further education at college or university, we try and think about goals and our future:

Which career?

Relationships?

Independence?

There are numerous ways of support:

Camp/Retreat (Peer Support)

- Meeting is more concentrated
- Not as frequent

Support Group (Peer Support)

- Meeting is topic centralized
- More frequent

Doctors

- Not always supportive
- Shouldn't be hindering about prognosis

Family & Friends

- Not always understanding
- Ultimately support you or leave you

God & Faith

- Belief in God strengthened
- Lose faith in God



Most Effective Method: Peer Support

One survivor to another can discuss on a much deeper level than from just talking with family or friends.

Young adults should have the ability to share about personal topics or emotional frustrations without worrying about persecution.

Recreational camps provide facilities and means by which survivors can safely provide support to each other in a nurturing environment.

Pros & Cons of camp/retreat: Pros:

The camp atmosphere allows for challenges to be conquered and new important friendships to be made.

Life changing experience and memories which last a lifetime.

Helps survivors escape from the stress and tension of day to day life.

Cons:

Campers have to deal with possible emotional repercussions after coming home.

Communication between friends can fade as distance separates campers.

Resources needed for a camp:

1. Location:
 - Should be in a remote but serene place
 - Accommodating to needs of campers.
2. Funding:
 - Food, lodging and transportation.
 - Budget for activities and supplies.
3. Facilitators:
 - Should be aware and understanding of campers needs
 - Should be outgoing yet emotionally stable.
4. Participants:
 - Should be medically sound enough to attend
 - Any survivor or patient should be welcome to attend.

The following campers' quotes summarize the importance of these camps: "Camp made me a stronger individual."

"At home, I tend to put on a fake mask to make it easier for others, but at camp I don't wear a mask."

"I made lifelong friends in a relaxed and accepting environment."

"Everybody I've met at camp is so open and understanding."

"Other survivors don't make me feel so alone."

"There was no pressure to do anything I didn't feel comfortable doing."

"Camp was definitely a positive experience and I would recommend it to others."



Conclusion Individuality can be defined through any event we encounter between the ages of 13 - 25. Anything which affects us emotionally or psychologically during this time can help us gain more control over our life. The impact we can have on one person can help change their lives forever. Medicine and treatment may help remove cancer but only continued support from others will help a cancer survivor to survive.

Vik Bubber & Daralynn Walker
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**Reprint of a power-point presentation held at the Vancouver conference September 2005*



Share Your Story of Survivorship with the Lance Armstrong Foundation

The Lance Armstrong Foundation (LAF) believes that in your battle with cancer, knowledge is power and attitude is everything. In an effort to help cancer survivors, we have created LIVESTRONG(tm) - Resource for Cancer Survivors (<http://www.livestrong.org>).

LIVESTRONG(tm) is a resource program of the LAF, created to educate cancer survivors and their friends and family about topics of survivorship. LIVESTRONG(tm) offers you an opportunity to learn about topics that may affect your life after treatment ends by providing resources that can help you understand some of the physical, emotional, and practical topics that are part of survivorship.

An important part of LIVESTRONG(tm) are videos of survivors telling their stories and identifying issues they have faced as part of their post-treatment and long-term survivorship experience. Survivors from all over the United States have already contributed to LIVESTRONG(tm) by sharing their stories of survivorship. We are excited about filming stories from an interna-

tional perspective at the ICCCPPO Parents and Survivors Conference. We would love to film your story of survivorship in Vancouver, BC. We are looking for survivors or their caregivers who can share experiences from various perspectives (ethnicity, socio-economic status, age, etc.). We ask that survivors provide us with their cancer type, date of diagnosis, age at diagnosis, ethnic background, city and country of residency, and contact information (mailing address, email address, and phone number).

If you feel you may be interested in sharing your story, please call or email me, and I will be happy to answer any questions you may have. Please respond by 4pm on September 14th, 2005. Thank you for your commitment to help others learn how to live as a cancer survivor and learn how to live strong.

Nancy Tran
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Finnish Survivors Visit Austria



SYLVA has trained over 50 young survivors to provide peer support for children and adolescents who are hospitalized because of cancer. The program has become a great success. The hospitals and the patients liked the visits of the young support persons, who are on average 18-25 years of age. Finnish survivors were invited to Austria to tell others more about this activity:

We were 11 young Finnish survivors who flew to the flowering Vienna in the middle of April. We were invited by the Austrian survivors and, of course, were very excited about the trip. The purpose of our journey was to talk about the Finnish patient support activity we have been carrying on in Finland.

Our hosts had made a fabulous schedule for us in Austria. First we spent one night in Vienna. Then we travelled to Linz for two days to meet with the local

survivors. On our trip, so much was happening and we enjoyed everything! Marvellous meals at traditional Austrian restaurants, sightseeing, museums and shopping. But what was most important, we had a great time with our new friends and got to know each other.

It was a great pleasure for us to introduce our patient support activity. We presented the main points by acting out drama, and told the Austrians what it means to be a support person. Everyone got the idea of what we meant, and it was a funny way to learn about it.

We survivors had an excellent trip with good company. We hope to meet our Austrian survivor friends in the same spirit in Finland soon!

Heli Vikeväinen



CanTeen Ireland – a group for teenage survivors

Research suggests that 1 in 3 people will get cancer. However, cancer in young people is still rare. Approx 200 children and teenagers are diagnosed with cancer each year in Ireland.

In Ireland teenagers with cancer are cared for in either Children's Hospitals or Adult Hospitals – there are no Adolescent Units!!! That is why CanTeen was founded.

Mission Statement of CanTeen:

- Nation-wide support group for young people and run by young people who have or have had cancer.
- CanTeen Ireland offers support based on shared experience in a relaxed and fun atmosphere.

Aims:

To offer support to young people with cancer.

To encourage and motivate young people to live with their experience of cancer.

To encourage the personal development of group members.

Supporting young people with cancer:

- Peer support; TeenLink, Buddy System
- Newsletters, Website, CanTeen-Video
- Providing them with the opportunity to talk about their experience of cancer with others who have similar experiences
- Weekends away and Day Meetings
- Establishing links with organisations abroad, exchange visits

Developing young people with cancer

- Challenging their perceptions of their abilities through activity weekends away
- Identifying and encouraging talents, and personal skills



- Providing opportunities to acquire new skills
- Encouraging young people to lead as normal a life as possible

Empowering young people with cancer:

- Providing accurate, age appropriate information about cancer
- Steering Committee has majority of teenagers
- Access to training
- Providing opportunities to take on responsible roles, developing their skills

Funding

We do not receive annual core funding. Much of it is from fundraising and once-off grants for specific projects. Annual sum from The Irish Cancer Society, and other Voluntary Organisations. Also grants from the Lottery, E.H.B, and Irish Youth Foundation. The women's mini marathon is our biggest fundraiser.

In 2004 € 33,000 was raised

What Some of Our Members Say:

- SUPPORT,
- You can RELATE to others who have been through the same thing
- You are NOT ALONE and other teenagers get cancer too.
- FUN, and you make lots of NEW FRIENDS.
- EMPATHY.
- CanTeen provides GREAT BACK UP.
- Helps your SELF CONFIDENCE- people come out of themselves.
- You can TALK THROUGH your problems
- Helps ACCEPT WHO YOU ARE during your illness and afterwards.
- CanTeen is a SUPPORT NETWORK and helps BUILD your SELF ESTEEM.



- Change of scenery from the routine of hospital, and home. Time to get away from it all...

CanTeen Ireland Volunteers:

- Currently 26 volunteers (various professions, including healthcare).

The Supportive Role.

- Developing caring, responsible relationships with young people.
- Listening, and respecting their points of view.
- Encouraging and motivating.
- Being there for young people.

The Organisational Role.

- Assisting the Co-ordinator with the smooth running of CanTeen activities.
- Organising the members for group work, and for duties e.g. wash up duty!!
- Preferably Organised Chaos!!

The Supervisory Role.

- Ensuring the safety and well being of young people during all CanTeen activities.
- Dealing with instances of bullying, or disruptive behaviour.
- Actively promoting inclusive behaviour amongst young people.



Book available at CanTeen office

The Youth Work Role

- Working in partnership with young people (Steering Committee).
- Encouraging young people to express their thoughts and ideas.
- Challenging young people's perceptions of their abilities.
- Providing informal opportunities to learn new skills. Learn by Doing!

What our volunteers say about CanTeen:

Fun, just to be with young people.
 Meeting people with wonderful attitudes to life!
 It's fun to work as part of a group.
 Meeting other leaders and making new friends!
 Camaraderie between leaders.
 Knowing that what I'm doing really makes a difference!

*For more information contact: CanTeen Ireland, Carmichael Centre
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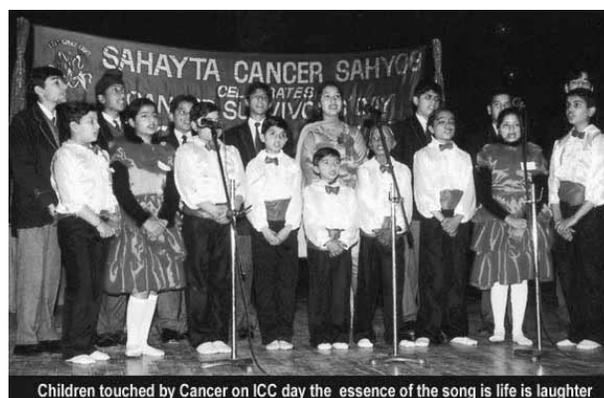
This information was presented at the ICCCPO-conference in Vancouver, September 2005 (powerpoint presentation)

A Survivor's Voice

Today, I am standing before you because of the blessing, good wishes and prayers of my family, teachers, friends and all my elders, the professional competence of my doctors and above all, God has been kind to me.

My struggle with cancer began when I was 12 years of age. I was in the eighth class and was an energetic sportsman. I was expecting to win medals on the annual sports day in my school.

One day during the summer vacation I felt excruciating pain in my right knee. An X-ray was done. The doctors told my parents that it was very serious and a biopsy had to be done to rule out osteogenic sarcoma, the worst kind of bone cancer. And in case it was cancer, my leg would have to be amputated without wasting any time otherwise my life was in danger.



We left for Mumbai and reached Tat Memorial Hospital the next morning. We met Doctor Kurkure. After a look at the X-ray, she said it was 99.9% cancer

and referred me to Dr. Puri an orthopaedic surgeon who conducted the biopsy.

We came back to my cousin's house in Mumbai. He asked me what the doctors had said. I said, "It is 99,9 % cancer." He said: "Where is the difference: 0,01% added makes it 100 %." We both laughed, but within I was worried, very much so and in fact I cried when I was alone. I wondered whether I would still be able to walk on my two legs.

The biopsy confirmed the diagnosis cancer. The treatment started immediately. I went through eight chemotherapies, each lasting 5 days. Imagine five days of non-stop medication drop by drop through a catheter. Five of these chemos were conducted under the able supervision of Dr. Marwaha and Dr. Anita Trehan at the PGI.

After three chemos I went through a major operation on the right leg. Dr. Puri at TMC Mumbai did the operation. Now I have an artificial knee and a 15" long prosthesis in my right leg. After eight very difficult months, the doctors told me that I was free of tumor and could go back to my normal life.

I started going to school again. But one thing in my life was missing, the one thing I loved the most. I could not play football, take part in athletics and could not be in the Bhangra team. I missed it and felt very bad. But then I was and still am a sportsman - I decided to take these setbacks in my stride.

After about eleven months I felt a pain in my chest. I could not move my left arm comfortably. I would get tired very soon. I guessed that the cancer had spread to my lungs. But I kept it to myself. I did not tell my parents, as I believed that it was the end of me. And I did not want to trouble them.

A routine periodic check-up confirmed my worst fears. Cancer had spread in both lungs. My left lung was full of pleural liquid and the right lung had cancerous nodules.

The next morning I went to school and cried there, as I believed that it was my last day in school. That day I played football with my friends as I believed I would not be among them any more.

We reached Mumbai the next morning. The doctors there told my parents that there was no hope for my survival and nothing could be done and that it could be less than six months. A doctor wrote on the file "At this stage surgery does not make any sense." I had also given up hope. But then Dr. Kurkure said that she would try something if we could bear it. She gave no assurance but gave hope.

My parents told me. "Don't be scared of death. You have been a lion throughout. And even now you are a lion." They expected me to fight it out and not to give up. One of my uncles came to the hospital to see me and said: "You will win this battle."

I realised death comes to everybody and one day it will come to me also. But it was not time for me to leave. I decided that I would not leave this world unless I had achieved something and given back something to the world. How could I let down my parents, my family, my doctors, my teachers, my friends and all those who had prayed for me and wanted me to go back with them!

God helps those who help themselves. I decided to fight like a warrior and I fought with my full strength. I prayed to God to be with me. I learnt to meditate and I always felt stronger after I had meditated.

I went through eighteen more extremely tough chemotherapies again, half of them in Delhi under the supervision of Dr. Gauri Kapoor in Rajiv Gandhi Hospital. After nine chemos I was operated upon in the left lung by Dr. Mistry in Mumbai. The right lung was apparently O.K. Everyone was surprised to see the results. Even the doctors said it was no less than a miracle.

Towards the end of the treatment, doctors detected an active cancerous nodule in my right lung. I was again operated upon in my right lung and am still under observation.

I started going to school in November 2003 and did not want to be left behind in any sphere. My teachers and friends were very helpful. I passed my 10th grade (CBSE-Examination) with 65% marks. My principal said on seeing me: "Well that is 100% in everything." And that was a reward in itself. It appeared in the newspapers.

That was when Sahayta came to know about me. They traced me and contacted me at my place. They sent information about my fight to ICCCP, the international organization that helps cancer patients and survivors. ICCCP gave me a scholarship and invited me to their conference in Oslo, Norway. But for certain reasons, I could not go there.

Today after four years of eventful life, I think I understand life better. After having been so close to death, now I know what life is. I know what it means to be alive. Now I try to reach out to other young people who are suffering from the same disease. I share my experience with them and give them hope. Encouraged by my results, another boy from Patiala has been given the same treatment. I pray for the best for him.

Now, I live every moment of my life. I have greater respect for the people who stood by me and believed in me. I have seen others facing difficult times and standing by me throughout these years, with faith and determination. I realize people's love when they prayed for me in churches, madirs and durgudwaras. Now I know what it means when they say, give back to the world what it gives to you. Now I believe in God and firmly believe that God is always kind and will always be with me.

Gagan Ishwar, India

Returning to School - A Teachers Guide for Students with a Brain Tumor*

As it was recognized that brain tumor patients need very specific support – not only in the hospital but especially when they return to school, we decided to produce a folder with information and guidance to teachers about how best to help pupils with a brain tumour.

All brain tumor patients in the Secondary school age (11 – 19) treated at the Royal Marsden Hospital in Sutton who were off active treatment and presently attending school were asked to get involved. 63 patients and families had been approached of which 33 gave consent. We also asked teachers to involved: 30 head teachers and 29 teachers agreed.

It was decided to include into the folder general information on:

- Background information
- Returning to school
- Difficulties in the classroom
- Useful contacts, terms and references

As well as individual information about each patient such as:

- Individual information sheet
- Types of tumors
- Treatment
- Side-effects: immediate and delayed
- Follow up – monitoring

Returning to school

Before a student goes back to school, the teachers have to be informed about

- possible changes in appearance and behaviour
- how they can arrange keeping in contact with the patients and the patients with their class mates
- how to support the siblings
- how to arrange home-tuition, when needed and all about the risk of infection

We realized that teachers would have to be prepared for the difficulties which might occur in the classroom and will include information and guidance in the brochure on topics like:

Fatigue

Ways to signal need allowances



Emotional Difficulties

Different looks
Changes in ability

Behaviour

Angry outbursts
Irritability
Attention seeking
Withdrawn



Social Problems

Bullying
Social isolation
Sharing and taking turns



Cognitive Difficulties

Gradual decline in IQ and performance
Adjust expectations
Modify the curriculum and teaching style

Concentration & Attention

Reduce distractions
Give simple instructions



Memory

Difficulty with Maths and Languages
Establish routines
Provide memory tools



Speech, Language and Communication

Impaired social language = 'geek' & 'weird'
Use prompts, frameworks and feedback



Vision

Confusion and social isolation
Enlarge worksheets
Use a laptop



Hearing

Use 'Direct Audio Input'
Provide visual support and instructions

Mobility and Motor Skills

Arrange for easy movement to classes
Handwriting affected?
Use pencil grips and adapted equipment.



Based on our experiences so far, we recommend that every young person treated for a brain tumour should be placed on the 'Special Needs Register'. They should remain there for their entire school career. It should ensure regular monitoring of cognitive, social, emotional and physical deterioration or progress.

Once finished, The teachers guide will be distributed through the Royal Marsden Hospital and available to 20 other paediatric brain tumour treatment centres in the UK. Follow-up seminars for teachers as well as parents are planned and we are working on the set-up of a Website.

*Further Information:
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**Notes from a powerpoint presentation at the Vancouver conference, September 2005*

Regional Group Reports

Helping to Cure Children in Africa

On January 29, 05 UNAPECLE invited Professor Jean Lemerle working in the hospital Gustav Roussy of Villejuif, near Paris in France and acting as President of the French-African Group of Paediatric Oncology (GFAOP). This group was been created in 2000 on the request of African doctors in order to improve the paediatric oncology in African countries. First a program of 3 years was created – organization, therapy and training. Innovating sectors have been implemented in different French speaking African countries in the following towns: Tunis, Alger, Oran, Rabat, Casablanca, Dakar, Yaounde, Abidjan, Madagascar and recently Bamako and Ouagadougou.

Members of this group meet once a year in Villejuif (France). The problem to be solved is: Can we cure children with cancer with modern tools in Africa?

For treatment, two diseases have been addressed first: Burkitt Lymphoma and nephroblastoma (in France 90% of the cases can be cured mostly with chemotherapy). The beginning of the treatment of Burkitt lymphoma has been very hard, 30% of the children died because of the treatment, Jean Lemerle had to review each file discovering errors. But within 3 years this rate went down to 10%. The success rate is now 65% and reaching 80% in 2 or 3 units. In nephroblastoma, a surprising cure rate of 80% has been obtained. The group will now treat Hodgkin's disease and Leukaemia.

There is a very big demand for African doctors, their know-how has tremendously improved. Nowadays 400 patients with Burkett Lymphoma and 300 with nephroblastoma have been treated with success in Africa. These paediatric oncologists are mostly trained in their country with a speciality abroad (but not always, it can be done locally). On the theoretic point of view the training is well done, in practice it has to be improved: not

enough examination of the patient, bad transmission, everything is done verbally, objective is to have them writing down everything.

GFAOP organizes training sessions in France for doctors and nurses in a Paediatric Oncology Department.

Other experience: they sent 2 very good nurses from France during 14 days, they listened, observed and after work they gave training to the entire sector.

GFAOP is also trying to help the families but until today it has not been possible to create organizations for parents.

In African countries a financial participation is requested from the parents, it is valuable for mild disorders but not for important pathologies. For example in Morocco 100% of the cancer treatments are paid by an organization.

GFAOP need funds for drugs, its budget is about 100 000€. It does not get any help from the government. The Institute Gutav Roussy is helping on the logistic point of view and Marie-Marthe Bruck's association "A Heart for Children with Cancer" (Luxembourg) gives financial support. In Yaounde, the "Malta Order" has organized a convention to help.

In order to help GFAOP which is now a member of UNAPECLE we suggest that all our associated members collect funds during the next International Cancer Day in 2006. UNAPECLE intends to contact African mothers whose children have been cured in France to stimulate them to create parent associations in their own countries. This would be our contribution of help to developing countries.

*Cécile GALZY
UNAPECLE- Secretary
Montpellier (France)*

Day Care Center at CanSupport (Delhi)

CanSupport, a registered cancer charity, runs a pediatric day care center for outpatients of the All India Institute of Medical Sciences, New Delhi, every Monday.

Objectives

The motivating thought is as powerful as it is simple:

- The children need a break from the relentless demands of the disease – a place that offers them the opportunity of self-expression under the encouraging eyes of resource people who could be arts & crafts teachers or playwrights who work with children.
- The caregivers can rest and exchange information – about cancer, medication, doctors, aid or just the stories of their lives.

Activity Definition

The center organizes picking up the children and their caregivers from the hospital after they have seen their doctor and undergone their tests. They are brought to the center where there is structured activity for an hour for the children, while caregivers interact in a separate area, after which everyone has something to eat. The children then play among themselves until they are ferried back to hospital in time for their reports and chemotherapy. Donors have made some medication available for the children, which helps to alleviate (in some small way) the financial burden on the family.

An arena for collaborative-support

What makes the day care effective is the manner in which this "space" of 3 hours is used by the many people who come specially to inhabit it – the children, caregivers and volunteers

The entire day care is run by volunteers. All the wherewithal is donated – be it transportation, food or medicine. The day care gives caring citizens an opportunity to join the battle in a supportive & non-intimidating environment by becoming intimate with the patients and understanding their disease.

It brings the community in close touch with cancer and reduces the isolation of the patient and his or her family.

The caregivers are able to talk about their cares and lives in a non-threatening environment. They pool their information and their feelings of hope for a future without cancer for their children. When a parent whose child is in remission joins them, it makes the everyday worry, frustration and disruption of life 'okay', because they have living proof of the success of medicine.

The children are in the center of our interest. Almost all of them are not able to go to school. For them, the day care center held once a week fills the need for

interaction with their peers. Many of them have become friends during the long hours spent waiting in the hospital. They renew and strengthen these relationships in the pleasant environs of the center. All the caregivers remark about how upbeat the children are about going to the hospital on Monday !!

A typical Volunteer Day Care Roster for Monday

Bus-time donated by neighboring school to pick up & drop children:

- 5 volunteers
- 1 resource person [artist / dancer to work with children]
- Food donated by well-wishers
- Medicines donated by well-wishers
- No. of patients 10-15
- No. of caregivers 15

The activities of the day care center have been extended to Fridays to include adult patients and their caregivers from Dharamsalas [guest-houses for out of town patients who are not admitted in hospital]. The patients come with members of the family who include children. They have special needs – there is an intense feeling of isolation since they are away from home in an alien city fighting a disease that brings both fear and daily tribulations. This is their time to bond and relax away from the oppressiveness of the hospitals, outpatients wards and the barrenness of dormitories in a dharamsala.

The resource people, all volunteers, teach relaxation techniques like yoga, Reiki, breathing exercises, etc. Everybody eats lunch together before going back. There is a plan to provide these families with dry food rations so as to ease the financial burden they carry.

Urgent request from the Secretariat

We kindly ask our members to inform us of any change of address, e-mail, website, telephone and fax.

Some e-mail addresses seem to be incorrect. So, if you don't get any information from the ICCCPPO secretariat over a long period of time, make sure to send a short note with your e-mail address to be compared and – if necessary – corrected.

Could you also write us if you know of new parent organisations in your region? They may be interested to get known to ICCCPPO and we could send them the necessary information and documents.

Thank you for your help!
Marianne Naafs-Wilstra

Rafi Memorial Painting Competition



The Rafi Memorial Open Painting Competition for Children and Adolescents was held at local Safa Arcade Auditorium on 28th July 2005 with a lot of enthusiasm and gaiety. It was sponsored by the Children Leukemia Assistance and Support Services (CLASS). Over three hundred children and adolescents drawn from about twenty primary and secondary schools of the Chittagong region took part in the event. Subject of the competition was "Environment and Family". Guests attending a pompous prize-giving ceremony arranged on the occasion, asked enthusiasts

present to ensure more care for the children. They also stressed preventing children from taking food items mixed with chemicals, colors and preservatives. The speakers also emphasized developing awareness about meeting the menace of childhood cancer and taking preliminary preventive measures. Eminent painter Prof. Sabiul Alam, former Lions' Governor Nader Khan and CLASS Chairman Osman Gani Mansur graced the occasion as guests. Rotary and Rotaract Club of Islamabad extended all-out cooperation in the arrangement of the event.

It may be mentioned here that a number of children with cancer were invited to view the event, some of them also participated. Local media highlighted the program in detail.

*Osman Mansur
CLASS, Bangladesh*



Regional Group Reports

New developments help children and parents

More than one year after Valencia, I write to you. During 2004 - 2005 we had a big effort to build the Radiotherapy building, which was inaugurated last September 30th. We are very happy because our poor children (80%) will no longer have to use the Cobalt bomb. A new technology with Linear Accelerator will be operating next December. Now, we are involved to raise US\$ 1,2 million dollars to buy an MRI equipment. This image technology is of the utmost importance, mainly for the children with brain-, bone- and soft tissue tumors. Today we are "allowed" to do only two MRI per month with public support. However our demands are 30 to 40 MRI exams. So, it will be very important to have this equipment functioning in the new building.

On the other side, since January 2005 we have a transport support for the children who live far from Campinas. As they have to wait many ours to go back home, a beautiful building was constructed. There they play, have school support, have some food /lunch, and

there is also a hair-dresser for the mothers. On the second floor, there is a place for parents, where they can sit and talk and get information from other parents who have had a child with cancer.

Concerning SLAOP activities, we had an administrative working groups since Jan 2004 and the Annual Congress in Brazil was held in April 2005. During this year it was possible to rescue the economic health of SLAOP's finances. Also it was possible to define our work in a LATIN INFANT program, that is connected with LATINCARE for all of South America and the Caribbean, for a survival registry of pediatric cancer (below 15 years of age). It will start to collect data in May 2006. The period of study was defined from 1996-2001. When we will know our reality in different cities and countries, we can delineate future strategies.

*You see, a lot has happened since we met in Valencia.
Silvia Brandalise, MD
Director of Boldrini's Hospital, Campinas, Brazil*

Children with Leukemia meet in Turkey



The fourth International Week for Children with Leukemia in Turkey from May 28th to June 3rd has been a huge success with great participation. During the week, which aimed to increase public awareness on childhood leukemia and other cancers in children, children from almost 30 countries and 300 children from Turkey with their families met, thus providing a platform to enhance the solidarity amongst all children with leukemia. This week was also celebrated with various activities in other countries such as Jordan and Bosnia Herzegovina.

The week started with a kite and balloon festival. The kites painted the sky of Ankara with different colors symbolizing all the children with leukemia around the World. The "NO to Leukemia March" on the second day turned into a carnival with the participation of thousands of people in Ankara. There were several shows performed by our children, volunteers and professional artists. During the week participants had the chance to get to know traditional Turkish culture and also shared aspects of their own cultures.

On the last day there was a cocktail organized in Ankara with the participation of high level executive officers, heads of the diplomatic missions and international organizations. A play performed by the children was applauded for minutes.

After the program in Ankara the participants flew with a private plane to Antalya in order to spend a joyful holiday. They stayed at one of the best hotels in Turkey and had a great time enjoying the sea and beautiful nature. At the experience sharing meetings, parents and children had the chance to tell their stories in order to take strong steps to realize a much more fruitful cooperation [so that they would have a clearer idea of how to improve cooperation in the future]

Children made trips to historical and touristic localities in Antalya such as the ancient city of Aspendos,

Naturland Ecopark etc. As special guests with other children with leukemia from Antalya they watched the show of dolphins and whales.

The yacht tour on the blue waters of the Mediterranean was one of the best moments of the week. All these children from all over the world on the same ship with that big smile on their faces. Even though they didn't know each other's languages at the end of the week they all had become very close friends. At the farewell festival everybody was sad because they had to leave their new friends but at the same time they were happy to have experienced such an event with all the others. They returned to their countries feeling much stronger in the fight against childhood leukemia.

All the events were promoted via mass media in Turkey and also in the participants' countries. Throughout the week we informed the public about the facts of childhood leukemia and other cancers.

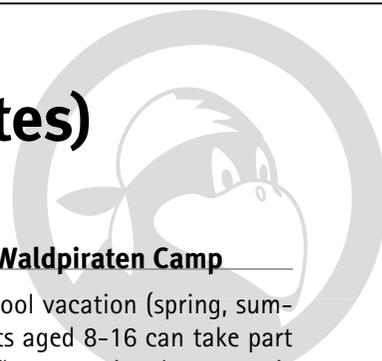
LOSEV aims are to make children happier all around the world without any discrimination based on race, ethnic, religion, national origin, gender and social, economic or any other status. All our efforts are for a healthier world and to see the smiling faces of children.

*LOSEV - Ankara Children with Leukemia Health and Education Foundation
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Waldpiraten Camp (The Forest Pirates)

A camp of the German Childhood Cancer Foundation



Regional Group Reports

Charlie Chaplin once said, "A day without laughter is a lost day." Children with cancer have little reason to laugh – their days are troubled with fear and isolation. Not hard to imagine how lonesome such a sick child might feel. This is why we, the German Childhood Cancer Foundation, established a camp for children with cancer where they can regain self-esteem and courage and learn to be part of a group. Unique is that this camp not only offers programs for patients and survivors, but also for their siblings and for the entire families.

The camp

The Waldpiraten Camp is a project of the German Childhood Cancer Foundation, which could be established with the help of many sponsors – first of all the German parent initiatives for children with cancer which joined forces and finances to get this camp off the ground. After two years of renovation, reorganization and construction, it opened its doors in September 2003. It is the first and only holiday camp for children with cancer in Germany and is open to groups from other German speaking countries as well as to all interested (for example, two groups from Italy joined these past sessions).

The location of the camp is a wooded area close to the city of Heidelberg. Thus, in case urgent medical care is needed, the pediatric cancer unit of the University Children's Hospital can be of help. The Waldpiraten Camp can accommodate up to 65 people (campers and staff), is accessible for the physically handicapped, and has all necessary facilities for a variety of different programs: a large main building with a dining hall and several seminar rooms as well as an infirmary, offices and a number of bedrooms for chaperones. The multi purpose building offers rooms for arts and crafts activities, drama and music. On the camp grounds, there is an open air theatre, a beach volleyball field as well as a climbing wall with high ropes.

Programs offered at the Waldpiraten Camp

Every year during the school vacation (spring, summer and fall), cancer patients aged 8-16 can take part in ten-day-camp sessions. The recreational program is – much like in other camps – designed to bring back the laughter, the big smile into a child's face – for no longer should a day be lost. Every day is a new challenge for the child – filled with activities, games and fun.

Integrated into the camp sessions are many outdoor recreational activities like hiking, climbing, canoeing, swimming, riding, bicycling, camp-out in the forest, nature discovery etc. and creative activities such as woodcraft, pottery, photography, music, creative writing, drama and last but not least – pure leisure time. Our main focus is on therapeutic recreation and group education.

The campers stay in log cabins. They get plenty of opportunities to meet children like themselves and get involved in team building competency to help improve their self-confidence, decision making and coping skills. As one camper said, "Here nobody stares at me, they all know why I have no hair and nobody asks stupid questions".

We are able to offer seven camp sessions throughout the school vacation time including programs for siblings (alone or together with their sick brothers or sisters). As siblings of cancer patients very often experience similar hardships and problems, they profit a lot from the exchange with others in their situation and thus feel less isolated, less special. In camp they are given the opportunity to talk freely about their fears and wishes without having to consider their parents, nor take heed of their sick brother or sister. Here they are met with the same sincerity as their sick siblings and take part in the very same activities, learn the same skills and come back home with the same experiences.

A special addition to these programs are the weekend seminars we offer to bereaved siblings. These are very intense meetings with lots of time for talks and reflection aside from recreational activities.

Survivors Meetings

Details about the weekend seminars for survivors (age 18 through 30) will be presented in another contribution by the survivors themselves. These are offered twice a year to a group of approximately 50 young people.





Family-weekends

As the Waldpiraten Camp was established by parent initiatives it is only logical to provide weekend seminars for families with children with cancer. These programs are offered throughout the year – whenever there is no school vacation. All families throughout the whole country are invited – usually through the parent initiatives or the psycho-social staff of the pediatric oncology units. The programs are designed for families during and after intensive treatment. One seminar per year addresses bereaved families (with their own program) and we also started special sessions specifically designed for single parent families with their very unique needs.

The program usually includes medical information, such as the latest developments in pediatric oncology, or all about "alternative" or "complementary" thera-

pies, information on long term effects or any topic that is of special interest. There are group discussions with psychologists or family therapists. We provide information on legal and social rights and offer many creative and recreational activities. These weekend seminars are excellent opportunities for families to meet others in the same situation, to exchange experiences and very often they are able to comfort each other. Not seldom, these weekends are the start for long lasting friendships between families from all parts of Germany.

And – last but not least – all parent initiatives which are part of our organization have the opportunity to plan and conduct their own week- or weekend activities at the Waldpiraten Camp. The only problem is: there are not many weekends left to cover the demand.

It seems that we are on the right track.

*Gerlind Bode
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(presented at Vancouver-
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Parent associations hold a key role in rehabilitation



Leena Vasankari, Vilija Zapalskiene

Associations founded by the parents of cancer children can act as efficient interest groups to improve the conditions of the patients. This was confirmed at an international seminar in Vilnius, Lithuania, last May. The topics of the seminar included children's cancer treatments, rehabilitation and social security. Among the participants were parents of children with cancer as well as health care professionals from pediatric oncology wards from three countries around the Baltic Sea:

Finland, Lithuania and Estonia. The two-day seminar was arranged by the Finnish association of children with cancer, SYLVA, and the Lithuanian association PAGUODA.

"We need mutual cooperation to make the needs of cancer children and their families better known in society. This also helps to develop the social security system and legislation," said Mrs. Leena Vasankari, executive director of SYLVA. "We must, however, remember that parent associations can only contribute to the development through persevering efforts and work. Parent associations are experts in matters concerning their children."

"Parent associations should have close contacts with the families of the patients, for whom they should offer rehabilitation of the best kind," SYLVA's Board member Mr. Veikko Heikkinen emphasized. According to Mr. Heikkinen, we also need close contacts with decision-mak-



The parent association of Vilnius



University Hospital Vilnius

ers and regular cooperation with the health care units which treat cancer children. "Legislation as well as social services is not planned only for children with cancer. This is why it is wise to cooperate with organizations working for the children with other long-term illnesses or handicaps," Mr. Heikkinen continued.

Attention to the quality of life

In Lithuania, about 100 children get cancer every year, most of them blood cancers. Over 80 per cent of the childhood leukemia cases can be cured with effective treatment in the country.

"It is our aim to improve the conditions of cancer children and their quality of life in Lithuania. The anxiety of the parents and child patient is decreased, if they are provided with sufficient up-to-date information about the child's cancer", said Mrs. Vilija Zapalskiene, chairwoman of PAGUODA from Lithuania.

According to Mrs. Zapalskiene, it is important to prevent cancer children dropping out of ordinary society. PAGUODA has a 3-year programme of rehabilitation and social integration support for the families of cancer children. They also offer a helpline for cancer children, parents and relatives who get free psychological consultation on the phone.

Mrs. Kirsti Sirkiä, Doctor of Medicine working at the University Hospital of Helsinki, outlined the present situation of children's cancer treatments in Finland. About 150 children get cancer every year in Finland, most of them being blood cancers. In recent years, the results in children's cancer treatments in Finland have also improved greatly, and they are now European top level.

Moreover, Professor Lina Rageliene from the University Hospital of Vilnius gave a detailed presentation of children's cancer treatments in Lithuania. Mrs. Marje Oja, executive director of the Estonian parent association talked about cancer treatments in her country.

Common interests advanced by regional cooperation

The cooperation of Finnish SYLVA with Estonian child cancer organizations began already in the early '90s. After that, SYLVA and the Estonians together arranged together special camps for teenagers with cancer, so that either the Estonians have come to Finland, or vice versa.

Latvia and St. Petersburg in Russia joined later in cooperation, and the latest newcomer is Lithuania.

Chances for closer mutual contacts were also investigated in October 2004, when a seminar was arranged in Helsinki for the parent associations and health care professionals working with cancer children in St. Petersburg, Estonia, Latvia, Lithuania, and Finland.

- We want to improve the quality of life of cancer children and adolescents, and offer them better rehabilitation. In our view, rehabilitation should be tailored to the individual needs of various cancer patient groups. We believe that cooperation between parent associations and health care professionals helps improve the conditions of cancer children and adolescents, Mrs. Vasankari said.

An international camp for adolescents from 13 to 17 years of age was also arranged near Tallinn, Estonia, in May 2005. The participants came from Finland, Estonia, Lithuania, Latvia, and St. Petersburg. A second camp for adolescents from these countries will take place in St. Petersburg May, 2006.

Tuula Virkkunen

Regional Group Reports

Help for children with cancer

We are glad to inform you that recently we carried out a solemn opening of the spiritual rehabilitation center of our group "Help to children with cancer". On this occasion sponsors gathered, mothers of children under treatment and of those who have already died, the assistants, the survivors and representatives of the press. Everything was just wonderful. The newspapers reported remarkably about a holiday. Survivors and some parents went with me to the hospital, where they arranged a party for the children. We gave them presents and celebrated



with fruits and pies. The faces of the children glowed with happiness, which was the best gift of this day!

*Tatyana Stankova
Wolgograd*

Announcements

February 15, 2006

International Childhood Cancer Day

Theme: Childhood Cancer in the Classroom
 Patients will be asked to take photos from their schooling situation
 For information contact:
 throughmyeyes@kidscancercare.ab.ca.

March 1 – 4, 2006

7th Continental Meeting of the International Society of Pediatric Oncology

in Africa
 Marrakech, Morocco.
 Contact: smhop@menara.ma.
 For details see www.smhop.info

April 6-7, 2006

ICCCPO Asia Parents Meeting

In conjunction with SIOP Asia Congress
 Shanghai, China
 15 scholarships for participants from developing countries or for regional participants are available for application.

Deadline Dec. 20, 2005

For more information and the program contact:
 Benson Pau (Co-organizer)
 +852 2796 1331 or +852 21486743
 icccpo-asia2006@pkwfoundation.org

September 17 – 21, 2006

ICCCPO Parents Meeting and Annual General Assembly

Geneva, Switzerland
 The ICCCPO Annual Meeting will be held in conjunction with SIOP (International Society of pediatric Oncology) in Geneva.
 Further details will be published on the website: www.icccpo.org as they become available
 The organiser for the parent / survivor program is Christine Wandzura. Contact her on:
 wandzura@kidscancercare.ab.ca
 For SIOP-information contact: www.siop.nl



Dawn Van Zant (text)
 Alexander Levitas (illustrations)

“Bradford and the Journey to the Desert of Lop”

Our new hard cover book will be available the first week in November. The new line of children's non-violent toys and books produced by Wild Heart Ranch empowers children with cancer and raises awareness for the endangered wild Bactrian camel.

We are donating a limited amount of these books to Children's hospitals and oncology wards. Please notify us if your department is interested and contact:

Toll Free: 1.888.889.9213. Kim Baker Kim@wild-heart ranch.com

“Bradford and the Journey to the Desert of Lop” has been awarded Dr. Toy's 100 Best Children's Products for 2005. (ISBN: 0-9761768-2-3)

These new booklets are available at:

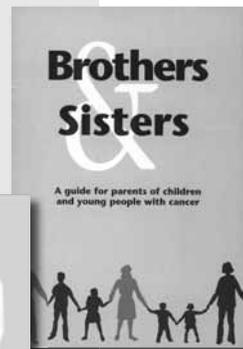
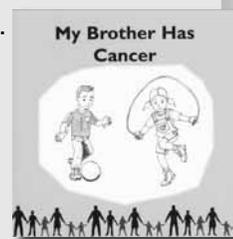
UKCCSG (The United Kingdom Children's Cancer Study Group)
 For more information contact: www.ukccsg.org.uk

Brothers & Sisters

A guide for parents of children and young people with cancer

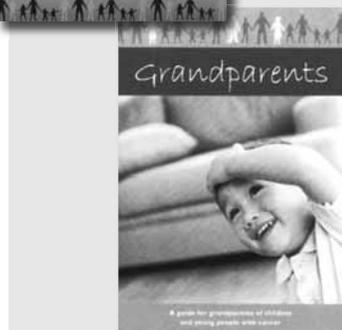
My Brother has Cancer

For children up to age nine.



When your Brother or sister gets Cancer

For older children



Grandparents

A guide for grandparents of children and young people with cancer

BOOKS

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The new executive committee (from left to right):
Ira Soelistyo, Benson Pau, Irina Ban, Anita Kienesberger,
Simon Lala, Julian Cutland, Chris Wandzura, Geoff Thaxter,
Edith Grynspancholc.

THE INTERNATIONAL CONFEDERATION OF CHILDHOOD CANCER PARENT ORGANISATIONS

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 E Mail: bureau@vokk.nl
 WEB SITE: www.icccpo.org

Members of the ICCCPO Board are mostly parents of a child who has had cancer or a life-threatening blood disorder. All positions are voluntary.

Sponsored by the Henk Naafs Memorial Fund, The Netherlands

PARENT GROUPS

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

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

HISTORY

- > Initial discussions in 1992 in Hannover, founded in Valencia, Spain May 1994.
- > Subsequent Assembly meetings held in Washington DC (1995); Athens, Denmark (1996); Johannesburg, South Africa (1997); Frankfurt, Germany (1998); Montreal, Canada (1999); Amsterdam, Netherlands (2000); Luxembourg (2001); Porto, Portugal (2002); Dublin, Ireland (2003); Oslo, Norway (2004).
- > Other meetings held at Paris, France (1994) Montevideo, Uruguay (1995), Vienna, Austria (1996), Istanbul, Turkey (1997), Yokohama, Japan (1998), Brisbane, Australia (2001).
- > Annual Assembly Meetings are usually held with the conferences of SIOP (International Society of Paediatric Oncology), and ICCCPO is represented at most regional SIOP meetings

FOCUS AREAS

- > Liaison
- > Advocacy and Education
- > Assistance to Parent Groups
- > Co-operation with less developed countries
- > Provision of information

LIAISON

- > Close association with the International Society for Paediatric Oncology (SIOP), and its Continental affiliates.
- > Recognition on a world-wide and regional basis.
- > Accepted as the voice of the parents.
- > Networking with medical and nursing practitioners world-wide.
- > Collaboration with Global Alliance for the Care of Childhood Cancer (GACCC) and World Health Organisation (WHO).

ADVOCACY and EDUCATION

- > Creating awareness on Survivor Issues : Insurance; Discrimination; Medical Health Services; Employment
- > The Role of Parents
- > School Issues
- > The needs of Bereaved Parents
- > International Childhood Cancer Day - 15th February

ASSISTANCE TO PARENT GROUPS

- > Creating and sharing information of the medical and treatment aspects of the illness, as well as emotional and social pressures faced by the families.
- > Pooling and sharing experience for running successful Parent Groups.
- > Workshops for group leaders.
- > Sharing knowledge related to long-term survivors and the late effects of some treatments (such as learning disabilities).

PROVISION OF INFORMATION

- > Newsletter
- > The Resource Centre and Bibliography contains a wide variety of educational material in several languages.
- > Web site: www.icccpo.org

SUPPORT FOR DEVELOPING COUNTRIES

- > Twinning
- > Travel Scholarships to Meetings
- > Networking
- > Guidelines for SIOP to assist in establishing standards of care in Paediatric Oncology
- > Recruitment of Parent Groups
- > Creation of a broader network with greater relevant experience

