

ICCCPO Newsletter

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en contacto con la
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A few words by the editors

This issue of the newsletter will be distributed shortly before the General Assembly meeting in Ireland (at Barretstown Castle). You will find the program included here and might take it with you and we hope to see many of you at this meeting. Please note that there is again a meeting for survivors scheduled along with the ICCPO program.

With this issue we are sending you a package of interesting articles on a variety of topics. We hope you find much of interest for you. We would also like to encourage you all to send us your own contributions: articles, reports, bookreviews, poems, pictures, letters, announcements – anything you would like to share with others or think important for other groups. This potpourri of contributions adds color to our magazine and makes it special.

With best greetings and wishes

Gerlind Bode
(for the editorial board)

International Childhood Cancer Day 2003

The second International Childhood Cancer Day took place on 15th February. The event was organised by ICCCP with the outstanding support of Cancer Research UK.

38 countries took part this year raising awareness of the 250,000 children who get cancer



every year in the world. The event also raised an estimated \$100,000 to support the work of parent organisations around the world.

The official launch took place in London and was attended by Marianne Naafs-Wilstra (ICCCPO Chair) and Sir Paul Nurse (Chief Executive of Cancer Research UK). Celebrities supporting the launch were Joan Collins, Rachel Hunter and The Cheekie Girls. Tony Blair also endorsed the International Day at a meeting in Downing Street with ICCCP and Cancer Research UK representatives.

In many countries parties and celebrations took place for children in hospitals. This proved to be a great way to raise awareness and to make it a joyful day for the children.

Contents

International Childhood Cancer Day 2003	
Parent Voice in Childhood Cancer	4
Organisation Issues and Models for Parent Groups	6
Igor's battle	10
Meditation on impending death	13
Book reports	16
Announcements	17
Program of ICCCP Meeting	18
Executive Committee	20



In Russia the pop group Russian Size played for the children. In Italy a football team of cured youngsters played in a match to commemorate the day. In Finland a photograph exhibition of children with cancer was launched and is now touring the country.

Many countries also held media conferences and seminars bringing together families, doctors and NGOs that provide support. These conferences provided information about the needs of children with cancer, and the media with an opportunity to help raise awareness.

A CD containing full details of events in each country will be available in July and will be sent automatically to all ICCCPO member organisations. This is designed to share ideas between parent organisations all over the world.

ICCCPO and Cancer Research UK are already making plans for international support on February 15th 2004. Initial details will be announced at ICCCPO's Annual Conference in late September. In the meantime, member organisations are encouraged to start planning their own events to make this event even bigger and better in 2004.

For more information contact Geoff Thaxter at info@lisathaxter.org



ICCD 2003 in India

This year, International Childhood Cancer Day was celebrated at the department of Pediatrics at the Postgraduate Institute of Medical Education and Research (P.G.I) in Chandigarh on Saturday by Sahayta Cancer Sahyog in collaboration with ICCCPO and cancer Research U.K. A Painting Competition was organized by Sahayta on 14th of Feb. in the Pediatric Oncology Department of the hospital to bring cheer into the lives of children touched by cancer. The children made paintings portraying various moods of childhood. Free gifts were distributed to all children. We also had a support group from Vivek high School in Chandigarh. These children painted on the theme "Cancer afflicted children need your friendship, support and not pity." They came up with beautiful ideas. The best message was "Your friendship can help them live up."

On the 15th of Feb. 2003 students of St. Stephen's School did a rally to create cancer awareness among residents. Colorful balloons were let off in the air by various volunteers and students and we were joined by Kanwal Thakur Singh, an Arjun award winner in sports. The motto of the rally was "empathies and not sympathies". The rally was flagged off from the sector 17 plaza by the Head of Oncology Division in the department of Pediatrics, AIIMS, Dr. L.S Arya, and was led by UT chief architect Renu Saigal, herself a survivor. The rally was received by the PGI Director, Dr. S.K Sharma, and School principal Harold Carver after it reached the Advanced Pediatric Centre at PGI. A brief introduction

to the International Childhood Cancer Day was given by the President of the Sahayta Cancer Sahyog, Mrs. Neelu Tuli. The function was compered by Kanika Mohan a sibling of Nitya, a 13 year old leukemia survivor. She has been featured on the website of Cancer Research, U.K and has also been featured in the media release by ICCCPO with her message: "When the going gets tough, tough gets going".

The cake was cut by the Nitya Mohan on this occasion and a lamp of hope, empathy, courage was lit by the director PGI. Sovenier was released by Dr. L.S Arya which contained paintings and drawings by children touched by cancer. It also had national and international messages for this day. Professor S.K Sharma, Dr. Arya and principal Harold Carver applauded the work done by Shayta in India and extended their full support to the organization. Prizes were distributed to the winners of the Painting Competition. The report of Sahayta Vatsalya Sahyog was presented by the volunteer Aradhana Mittal. After tea, a meeting of the doctors, Childhood survivor's their parents and volunteers of Sahayta Cancer Sahyog was organized to share their experiences. Dr. Marwah and Dr. L.S Arya answered the queries regarding childhood cancer. It was an informative interactive session. The function was concluded after that and it gave lots of support to parents and brought the cheer in the lives of our little ones. Words of thanks were proposed by Dr. Amita Tehran.

Neelu Tuli

ICCD in Indonesia

The ICCD in Indonesia went very successfully. We had many events, such as

- a hospital visit to the pediatric oncology ward, sponsored by McDonald's and Unilever.
- a seminar for parents in Surabaya, where we helped and encouraged the parents to start an organisation. Approx. 100 parents attended.
- a One-Day-Course for young doctors/practitioners, nurses (with accreditation for practitioners). This was in corporation with Dharmais Hospital, Jakarta, and the Faculty of Medicine, Indonesian University as well as the doctors from our medical team. About 100 young doctors and nurses came from Jakarta and surroundings.



- a One-Day-Camp with children (out-patients) and their families (parents and siblings). This event was sponsored by CANCER RESEARCH UK and BOURAQ AIRLINES (local airline). We held this event at Bouraq Resort in the mountains. We had a drawing competition, dancing, singing, playing together and finally some time for parents to share their views with the board of our foundation. One doctor and two nurses came along with us.

Fortunately Prof Dr. P.A. Voute (The Netherlands) could come from Surabaya where he was one of the speakers at the SIOP Course in February 2003. We had arranged hospital visits to the General hospital in Central Jakarta (Army hospital Dr. Gatot Subroto) and a hospital in southern Jakarta (Fatmawati hospital) for him.

*Ira Soelistyo
Indonesia*

Helen Jerram

Parent Voice in Childhood Cancer and Other Serious Health Conditions

Paper presented at the ICCCP0 Conference, Porto, Portugal, September 2002

(This paper was presented at the ICCCP0 Conference, Porto, Portugal September 2002 by Rebecca Jerram on behalf of the writer who was unable to attend)

I recently completed my doctorate at the University of Auckland, at the Faculty of Medical and Health Sciences. My thesis was to do with serious child illness, from the parent perspective. In collaboration with other parents who had been managing their children's health situation for some time, I developed a stress and illness management programme called the Strong Parents- /Strong Children programme.

My motivation was an unanticipated illness diagnosed some 20 years ago in our eldest son, Christopher. This life-threatening condition, revealed by CT Scan and eliminated by radiation treatment, was a pineal germinoma. This is a very rare and primitive cancer that arises from the germ cells at conception. These cells are almost always discarded. Very occasionally they remain and turn malignant in adolescence. In Christopher's case they had settled on his pineal gland and by the time he was 15 years or so, they had become a layer, like a carpet, creeping very slowly over parts of his brain, in particular his pituitary gland, auditory and optic nerves. By the time we knew that there really was something 'not quite right', the cancer had caused quite a bit of damage.

My research was an attempt to make some sort of sense out of the extraordinary events that have made an impact on our lives as a family and particularly for Chris. At the time we knew the nature of the beast and that something could be done about it. The aftermath of his condition and the resulting health, sensory and physical difficulties were things that still lay ahead.

From a parent's perspective, the experience was like no other that one would want to encounter in one's lifetime. Threat to our young, or threat to the young of any species, highlights basic instincts for their survival, with little thought for ourselves! I was keen to find out from parents what was involved in managing their child's illness or health condition, on a daily basis, to see whether there was anything that might be helpful to other parents further down the track. I embarked on my research some ten years after the event. Chris had recovered, but our family had experienced something that not everyone has the misfortune to encounter. Doctoral study was my way of trying to make sense out of what had happened!

I also hoped that it might prove helpful to other parents and put something back into the system.

In consultation with paediatricians and charge nurses at Starship Hospital and the Neurosurgical ward at Auckland Hospital, 40 parents managing childhood cancers, cystic fibrosis, diabetes mellitus (IDDM), renal disease and haemophilia for some time were interviewed. The Paediatric Coronary Care Unit at Green Lane Hospital in Auckland and Parent Support Groups were also informed of the research. Parents had all indicated interest in hearing more about the research from the hospital.

I interviewed parents either at home, at the hospital or at the Cancer Society's motel where several were staying. I was interested in finding out just what parents were having to manage on a daily basis. I was also keen to know whether they thought some sort of intervention programme might be a helpful community resource, what sorts of things they felt might need to be in it and whether they might like to be involved further in research. Parents were appreciative of the fact that I was a parent myself and had some understanding of the sorts of things that they were going through. I introduced myself as the mother of a young man who had had a brain cancer some years before. Many of them enquired about how he was and what he was now doing. They then proceeded to tell me how their child's illness had unfolded, how it had altered family life and what the situation was at the time.

I include here most of the first parent narrative noted verbatim when I met with this mother and her husband, in the neurosurgical ward of Auckland Hospital.

First Parent Narrative

Kept him home from school, eyes crossed, nothing else, very healthy. After three days, went to doctor, he sent us straight to hospital to see specialist, that was on Friday, suddenly we had a life-threatening situation, he told us it might be a brain tumour. We had to go to Auckland for a biopsy to confirm it. We came up here the next day, Sunday.

Everything seems to have an overlay of unreality, still nothing seems real at all. I came up in the ambulance, followed by Dad in the car, with only the clothes I was standing up in, found when I arrived I had left one shoe behind! We had to ring our older son to tell him what was happening. He is very worried about it all.

Son was still perky and well when we came up, he had a list of questions for the doctors. Then he seemed to get sick and was restless before the operation, didn't make any response even when having his hair shaved! Since surgery he has barely recovered.

I can't reveal my feelings, I have to keep a brave face for my son. He hasn't woken up much more than this since the operation, we came back to the ward this morning, since then we've had very little regular attention. I have a dreadful feeling that they are thinking of him as dead, I have a 'poor mother' feeling.

At first no one was telling me anything, when I realized that they were talking about my son, I moved closer to hear. I knew nothing about oncology, we were given very little information, this is my first experience, I'd never heard about this.

The biopsy has confirmed the diagnosis, and I've put myself 'on hold', really, I've stopped eating, washing, hardly slept at all, I can't bear to leave his bedside. I feel I'm fighting for my child all the time. I now realize I need to ask all the questions I have to and see that I get answers, he needs me to speak for him, to be his eyes and ears, and since I have been here on my own I'm realizing a sense of advocacy. We have no family in New Zealand, it's difficult to explain on toll calls, they are all very concerned, there's no-one here to help, my husband has been keeping in touch with the family and that leaves me free to look after our son, concentrate on looking after him. My husband says we need to be strong together. We have appreciated being able to be with him in the Whanau at 'Starship' while waiting for the operation.

My husband's employer gave him three days off work he stayed for the operation then went home, he's back here to take us home tomorrow. We're now in the second week since the operation, we return to our local hospital tomorrow. The outlook is uncertain.

The basic natural instinct of having to do all in our power, even when in a strange environment and having lost control over what is happening to our child, is, I believe, shown here very clearly. It is very clear just where her suddenly-altered priorities lie and a good picture is provided of the rude and sudden interruption to normal life that is made by such a diagnosis.

After parents had given me their information, I asked them if they could put a ranking from 1 to 3 beside the pieces of information that I could see clearly belonged together – in 'chunks' if you like. This they did, and their typed information was then checked with them a few days later, for accuracy.

It was quite apparent from all the parents interviewed, that, no matter what length of time had elapsed, the moment of diagnosis, what had led up to it, the diagnosis itself and its impact, and how it had



Rebecca Jerram, daughter of the author, presents paper at ICCCPO-meeting

been dealt with were still uppermost in their minds. Parents were able to recall their experience vividly and the times since diagnosis varied between six months and 15 years.

The stresses that most parents had rated most highly for stress intensity went right across the illness types. The most intense stresses were not just confined to childhood cancer. The areas or periods in which the most intense stresses were felt were at the time leading up to diagnosis, the time of diagnosis, seeking information, dealing with the treatment, and the daily management of the whole situation. The potential for threat to their child's life and the constant care and on-going vigilance heightened the impact of the changed child health status. Worry over the future quality of their child's life, seeing their child so sick and dealing with perceived effects on siblings were further areas of intense stress.

Most parents welcomed the idea of some sort of intervention package or programme, many were keen to be involved later on, depending on their child's health at the time and there were several aspects that they felt should be covered.

Requests for programme content included dealing with the worry and anxiety, coping with everyday practicalities of managing family and the illness, and finding ways in which they could get the information that they felt they needed. Parents also wanted help with knowing how they could access some sort of educational help and support if needed when their child returned to school, and how to help their child, the siblings and themselves deal with whatever might lie ahead.

The parent voice came through in this first study very clearly. Parents spoke freely and many of them told me that it was the first time that they had ever really talked about the whole experience. Many of them had had similar experiences although quite different diagnoses. One other clear factor that came

through with each of these narratives was the fact that all of these particular illnesses or health conditions are hard to diagnose. With many of the children whose parents were involved in this first study, regardless of their illness, parents had had to make several trips to their doctor before the more serious nature of their child's illness had been determined. Once it was apparent that something more than the more normal childhood illness was a possibility, referral to hospital specialists had in most cases seen immediate action being taken. The family doctor sees many sick children pass through his or her surgery on a daily basis. If likened to horses galloping past the surgery window, periodically there is one horse that appears again and probably again. At that stage it becomes apparent that this one may be in fact a zebra, not a horse and more information is needed, perhaps another opinion. Occurrences of serious illnesses such as childhood cancer are fortunately not common occurrences, but the impact they have on the child, their siblings and parents can have lifelong implications. Some form of disability may result and plans by a young person may need to be re-visited, with family support and understanding.

When our children are admitted to hospital, it plunges us quite often into an alien world. Part of coping with all that serious child illness implies is understanding that there are very few things that will ever be more difficult! It is challenging, by anyone's book

The role of parents is critical. As parents, we hold the 'real world' information on our children and this information can be most helpful for clinicians, nurses and others working with our children to know.

Parent voice in serious child illness, including childhood cancers, is a voice that needs to be heard, right there, alongside all the health professionals helping their children. However, parent voice is not heard very often in the professional literature.

Empowered parents, able to advocate and contribute in a fully-informed manner is one of the best ways to see that our role is recognised and valued in the best interests of our children.

The overriding impression that I was left with was that there are many, many parents managing situations not unlike our own and all of them are doing the very best that they could do, along with the health professionals- and that is all that anyone can do!

The Strong Parents-/Strong Children Programme has continued successfully at Starship Children's Hospital over the last two years. The aim is to train other parents to run it elsewhere. With this in mind, a charitable trust - the Strong Parents-/Strong Children Foundation has been registered to access funding for the programme in Auckland and eventually throughout New Zealand.

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Julian Cutland and Simon Lala

Organisation Issues and Models for Childhood Cancer Parent Groups

These notes are based partly on discussions at a workshop held at the ICCCPPO Conference in Porto in September 2002, and also on the experiences of various member organisations of ICCCPPO over recent years.

Introduction

Many parent groups start off as local support groups, often closely related to a specific Paediatric Oncology treatment centre. They normally develop a close working relationship with the hospital and the staff there, and have their primary focus as the support of the families who are treated at the centre. If they do fund-raising, it is normally from the local community, and is spent within the local area.

However, many groups have evolved from purely local activities to having a national presence, perhaps joining with other regional parent groups to do so, and this can sometimes be a difficult transition for groups to make.

There are different "models" that can be adopted by parent organisations when they "go national", and each of them has advantages and potential problems. The aim of this note is to identify these models, and the issues that may arise from them.

It is not the intention to be prescriptive as to what the "best" model should be. There are many variations between countries, in terms of the medical care provided, the social services available, and the legal framework in which parent groups operate. The combination of these makes it necessary for each group to adapt and organise itself to be best able to deliver on the objectives that it sets out to achieve. There are however some basic ideas that a group should take into consideration when it decides to formalise its existence.

This note is based on the experiences of some parent groups, and will hopefully be developed over time as other ideas are contributed by different groups.

Legal Framework

One decision that each parent group must make is whether it is going to be just an informal association of people, or whether it will become a formal, legal organisation. Remaining as an informal organisation will generally imply that it is unable to raise funds from the public.



Julian Cutland

Most countries will have legislation that governs the conduct of groups such as parent organisations. Typically, such organisations will be described as "welfare organisations", "charities", "informal organisations", "NGOs" (non-governmental organisations), or "NPOs" (non-profit organisations). For convenience, we will use the term NPO to denote all such groups.

Because NPOs will normally collect money from the public to achieve their aims, most countries have some form of regulation and registration of this sector, so that there can be the assurance that such moneys are utilised for the purposes for which they are collected.

Typically, the state will require that there is a formal constitution for the NPO, which defines its objectives, specifies how the organisation will be run, how its officers are elected, and how its finances are controlled. There is normally the requirement for the NPO to submit reports and audited accounts on an annual basis to the regulating body within the government. Issues of "governance" are often emphasised, in order to ensure that the organisation is run along proper business lines, and that there is no opportunity for the misuse of public funds.

In addition to whatever is required legally to operate as a NPO, there are often other aspects of legislation that a parent organisation can conform to. Examples of this would be getting recognition / registration in order for donors to get tax benefits on their donations (e.g. the USA 501[c]3 registration), or for the organisation to be able to claim back VAT or other taxes.

The important message is that parent groups who want to raise funds need to be aware of the legal framework that they have to work within, and must make sure that they conform to it. There is often a legal person among the parents who could help with this, or someone will know a lawyer who would be prepared to assist if asked.

Local and National organisations – different focuses

Before we get into the potential relationships between local and national organisations, let's look at some of the different activities they tend to be involved in.



Simon Lala

It is not intended to do more than highlight some of these activities. For more information, please refer to the excellent handbook "Your are not alone", which is produced by the Candlelighters Childhood Cancer Foundation in the USA (and which is given to all new members of ICCCPPO).

Local groups:

As mentioned previously, these are normally focused within a geographic area, and often on a particular treatment centre. They aim to support all of the children and families in that area, and work closely to maintain and improve the facilities of the treatment centre. Their activities may include: organising mutual support groups, and providing hands-on support for the families, children and parents; running programmes for the children, siblings and parents (including camps, outings, etc.); funding medical equipment or staff posts; improving the general facilities at the hospitals (e.g. play rooms, etc.).

Their strength comes from their close association with the area, and many are very successful in getting great community involvement, including raising funds locally. Typically they are very "hands-on", and have close contact with individual parents and families. They are able to develop or adapt the programmes that are most appropriate for their local situation and communities.

National Groups:

Many countries have national parent groups, which have evolved in a variety of ways. The main activities at a national level can include: advocacy and national policies for childhood cancer; creating relevant programmes on a national scale, and if necessary assisting local groups to implement them; providing assistance and guidance to local groups to get established, and to be effective on an ongoing basis; fund-raising for both national and maybe local projects.

They tend not to have direct contact with the individual parents, but rather focus on the bigger issues, and in helping the local groups.

One thing that parent groups unfortunately have to address in some less developed countries is the funding of treatment, where this is not adequately paid for within the public health sector. This can be at either local or national level, or both, and can end up being a major reason for the group's existence.

Organisation Models

If there is just one locally based group in a country, then most of the issues covered below are not relevant. However, where there are several local groups, they will ideally evolve a way of working together for

the good of all of the children and families in the country. This section describes the four main "models" for this relationship that we are aware of within different countries represented in ICCCPO.

Many of the differences have come about for historical reasons, depending on the way in which local groups were formed and evolved, and the inclinations of the parents involved.

There are many possible variations within each of the different models, but we hope that we have captured the main characteristics of each of them.

Model 1 – Completely independent groups

In this model, there are several local groups who function completely independently, with little or no contact between them.

Advantages:

Each group retains its local character, supporters, identity and funding base, and addresses the specific local requirements.

Disadvantages:

The groups will obtain no benefits from addressing common problems, and they will not be able to speak with a common voice on matters of mutual interest.

Model 2 – Independent Groups, with a National Umbrella Body

This model normally arises where there were pre-existing local groups who have established themselves with significant activities, and probably a funding base within their communities.

They have then decided to form a national organisation where they can come together for mutual benefit, but each retains their own names and identities separate from the "umbrella body".

A typical name for such an umbrella body may be a "National Alliance" or a "Confederation" of parent organisations. ICCCPO itself would fall into this type of model.

Individual parents belong to the local groups; it is the groups themselves that belong to the Confederation.

Much of the sharing of experiences and programmes would be on the basis of "this works for me, see if you can adapt and use it yourself", rather than on consciously setting out to develop common programmes for everyone.

The main power will remain firmly with the local groups, who continue to have complete autonomy, subject possibly to some mutually agreed goals and standards. The national body has very limited power to enforce its views on the local groups, and it will be

successful only so long as the local groups perceive that there is value to them from belonging to it.

There could be two variants of this model:

One option would be for the umbrella body to have a distinct legal existence, and be registered as a NPO in its own right. This would allow them to do fund-raising itself, in addition to what is done by the local groups.

A second one is for the body to be an informal organisation, which provides a forum for the groups to come together for mutual interest, exchange of ideas, and to decide on coherent approaches to common problems. However it would be restricted in what it would be able to do by way of fund-raising.

Advantages:

Each local group retains its local character, supporters, identity and funding base.

However they have a basis in the Confederation where they can speak with a common voice to address mutual interests. These may include aspects of government policies, e.g. for Health or for Social Welfare.

It also provides a forum for the exchange of information, experiences and programmes.

It provides the opportunity to do fund raising on a national scale, and tap sources of funds (e.g. of country-wide organisations) who may possibly not want to support purely local organisations.

Disadvantages:

This model has the potential for conflict between the National Alliance and local groups in areas of fund-raising. Clear agreements as to which local or national groups will approach specific potential donors are desirable.

There is also the potential for conflict if the relative roles and functions of the local and national groups are not clearly agreed.

This model loses the possibility of creating a common "brand" for Childhood Cancer in the country. The public will possibly see several different organisations and names apparently doing the same thing, and hence creating some confusion in the mind of the public.

Model 3 – A National organisation with local groups - diffused control

In this model, there is a national organisation and several local groups, which share a common name and identity, but where the local groups voluntarily choose to belong to the national organisation.

The local groups generally function as in the previous models, but there may be some constraints on them resulting from their membership of the national organisation. The role of the national organisation is

to address some or all of the functions described above, including providing leadership and guidance to the local groups.

Typically, each of the local groups, and the national organisation, will have a separate legal identity, registration as a NPO, etc. Each should be able to do its own fund-raising.

The "balance of power" between the local and national levels could vary. In some cases the national organisation could be funded by the local groups, in others it may raise its own funds for national purposes, or for distribution to member local groups. There could also be variations in the amount of control of policies, programmes, etc. that the local groups can exercise over the national body, and vice versa.

Compared to Model 2, the national body will probably play a more proactive role in identifying, developing, and assisting in the implementation of common programmes.

Advantages:

All of the advantages of Model 2 apply, with the addition that there is a common identity and "brand" across the whole country.

Also, there is an even greater weight for the organisation when it speaks on national and advocacy issues.

There is greater potential for the development of common core programmes, for the benefit of all groups, and a reduction of the "reinvention of wheels".

Disadvantages:

Similarly to Model 2, there is the potential for conflict between the national and local groups in areas of fund-raising, and with the relative roles and responsibilities at local and national levels. Clear agreements as to the "rules of the game" for these are definitely desirable, so that the different parts of the organisation are not, and are not perceived to be, in competition for the same resources.

Model 4 – A National organisation with local groups – central control

There are considerable similarities with Model 3, but in this situation there is much tighter control over the local groups from the national level. Generally, there will be one legal entity for the whole organisation, in terms of registration as a NPO, covering both the local and national components of the organisation.

Typically, local groups are formed (and disbanded) under the control and approval of the national organisation, and there are common policies and standards (e.g. for financial practices, programmes, etc.) across all of the groups.

Some programmes and projects may be funded at a national level, from national fund raising, with other programmes and fund raising done at a local level, involving the communities in each area.

Again, there can be "balance of power" issues, and there need to be clear agreements as to what the relative roles are between local and national. There needs to be an appropriate degree of autonomy for the local groups to function effectively, while conforming to key values and goals of the overall organisation.

Advantages:

All of the advantages of Model 3 apply.

Disadvantages:

Since there are probably local variations in the needs of parents and families, there is the potential that local groups are too constrained by national policies from meeting specific local requirements.

There is a danger that the organisation could become detached from the "grass roots" parent groups, and tend towards being a centralised, bureaucratic organisation.

This could be a problem especially within a large country, with many local groups, where it may become very unwieldy to try to have too tight a central control over local groups.

There is still the potential for conflict between local and national level functions.

Discussion and Conclusions

As was stated earlier, there cannot be a "one size fits all" situation for how parent groups are organised within a country. Interacting aspects of history, geography and personality will all play their parts in shaping the future and defining what is possible and practical in a given place and time.

We do however firmly believe that there is great merit in having a national organisation for the childhood cancer parent organisations within each country.

We also believe that it is absolutely essential to have strong and active local groups, who are the people to provide hands-on support for the individual children and families.

The balance between these two components, and how the relationships between them are defined, is something that each country will have to work out for itself. It is highly desirable that this is done with good will on all sides, recognition of the potential benefits and dangers of the alternatives, and with a determination to see that the best is achieved for the children and families. There is then a far better chance of building something of value for the long term.

It is hoped that these notes will give some assistance to parent groups who have to decide where they go in the future, and how they want their organisation to evolve. They are based on a range of practical experiences, from people who have faced some similar decisions in the past.

However they are by no means cast in stone, and we would welcome contributions from other parents and groups, who feel that they can enter into the discussions, and add something of value to other parent groups from their own experiences.

*Julian Cutland (South Africa)
Simon Lala (New Zealand)*

IGOR'S BATTLE AGAINST THE LUNATICS FROM L.A.

(LLA-Leukemia Lymphoblastica Akuta)

2nd November, 1994.

At the beginning of this autumn, Igor, our four-year old son, started complaining about pains in his arms and legs. Considering the fact that Igor has a brother Vladimir, younger by two years, the first thought that occurred to me was that probably they had had a fight - a very common thing in our home, to put it mildly. Unfortunately, this time it was not the case. Having conducted thorough, in-depth analysis and check-ups, it was confirmed that some imprudent, restless "creatures", jumping from place to place had invaded his arms and legs, with the aim of pestering little Igor. The said creatures suffer from lunacy, so consequently we called them "LUNATICS". Igor politely asked them to go back, but they enjoyed his company - far be it from them to leave. So, he decided to expel them by force and declared a WAR against them. My son thought that those Lunatics came from the United States, more precisely, from Los Angeles. We objected to the idea, but finally we agreed. Igor had the bright idea that the Lunatics had heard about the boy from Belgrade, who had never ailed in his life, so they decided to bother him. They came from the L.A. in a large plane, having flown across the largest sea in the world.

At the time when Igor declared war against the Lunatics, he started arming himself with dangerous weapons: a sword, a rifle, a knife and a hammer. But that was not all. We asked our hospital for assistance; a very good female doctor worked there. After hearing Igor's story about the Lunatics, she promised to help him win his battle and revealed that she had very powerful arms capable of forcing out the Lunatics; apart from that, she said, Igor was not the only warrior. There were many other children fighting a similar battle.

This female doctor led Igor and me to a small hospital room where the two of us stayed alone so that we had a lot of time for talking and devising a war strategy. We furnished the room with Igor's toys, books, pictures, even curtains, taken from his room in

our home. The pride of place was reserved for the TV set, VCR and cartoons. We brought his bed-linen with the clown designs as well; the only things we missed were the piano and a fridge. All in all, everything was fine apart from the fact that we were frequently disturbed by people in white overalls who kept coming and intruding into Igor's lovely room.

However, despite the lovely room and our armament, Igor was increasingly bothered by the Lunatics, experiencing great pain in his arms and legs. The doctor came quickly and poured into Igor's little arm a magic potion that put a stop to all his pains. As Igor did not like "pricks", his doctor brought a special little covered "screw", fixed it to his tiny arm and poured all the magic concoctions through it. The Lunatics went completely crazy, running away in all directions: escaping through his mouth, nose, bottom, urine. They were scared to death of the color red and Igor had to drink a lot of red liquid. Sometimes the doctor took out his Lunatics from a hole on his back and hip. It was painful since the Lunatics were scared of the doctor's glasses and consequently started biting, scratching and pinching out of fear the very moment they saw the glasses, but it was of no use since Igor was the most courageous boy in the world, not frightened by their antics. As soon as she removed them, the doctor quickly threw them into water and they drowned because they couldn't swim. However, there were many Lunatics hiding somewhere inside Igor's large muscles, wandering at random to the left and to the right, but not for a long time. Once Igor got angry, he became a really dangerous guy, so that even the doctors were scared.

In those days Igor was a very good and obedient boy and the doctor let him go home to sleep in his bed, eat mother's home-made lunch and granny's cakes, to play with his little brother and to go to hospital once the doctor had made ready various red and white poisons intended for the Lunatics. At home the Lunatics were going to be blasted by a range of large and small shell-pills.

11th November, 1994.

Igor arrived home and there was a disaster. Little Vladimir was even more dangerous than the Lunatics themselves because he expressed the wish to be blasted just like Igor; he cried bitterly, begging to be taken to the hospital together with his brother. In the end, Vladimir was taken to hospital as well to have his own infusion stuck into his arm, to be examined just like Igor and, finally, to be rewarded with sweets, just like Igor. When Igor burst into tears, Vladimir became a raging dog and beat up every single person. There was the rub! During his stay in hospital, Igor got used to being a GENERAL, therefore behaving in the same way at home. However, he messed things up because Mom and the Dad are commanders-in-chief at home. He realized very quickly he was not the only one with Lunatics, since every one of us has some Lunatics of his own and a secret weapon to fight against them. Igor's fellow-friends had Lunatics inside their tonsils so they had to undergo surgery to dispose of them; Igor was overjoyed that his Lunatics stayed in his arms and legs as he was terribly afraid of surgery.

On the second day of his stay in hospital, Igor asked me anxiously whether he was going to die. He explained he had heard there are some diseases one could die of. I realized it was the topic of lengthy discussions. Not knowing what to say at that moment, I answered I was going to slap him if he ever again asked such a foolish question. I did not want to lie to him since lies are outlawed in our home. No-one has "a contract with God" and nobody, including him, has the right to put such silly questions. He was satisfied with this answer, even more so when we made it quite clear that the term "to be ill" implies sneezing, coughing, fever and many other symptoms already known to him; as he did not suffer from any of them, it meant he was not ill. He was just at war with the Lunatics.

Igor's Lunatics were presently a little bit drowsy after the doctor had stunned them with different magic potions; it was very important not to wake them. They could be disturbed by a blow so we made every effort to avoid anything of the kind; we tried to eliminate every possibility of being smacked by Vladimir. It was very hard to accomplish; Igor and Vladimir were simply used to a free fight. However, they quickly realized that the "PROHIBITION OF FIGHTING" had positive sides. The prohibition also referred to Dad and me. Vladimir was an incredibly quick learner. At very dramatic points he would claim to have LOW TROMBOCITES!!!

15th December, 1994.

Considering the fact that in any war, warriors must undertake special precautions, we did the same trying to fulfil and keep to all the doctor's advice. First of all, it meant bombing the Lunatics regularly after each meal since they gathered around swallowed food and

as soon as they started eating, Igor launched his bombs and killed them. It was followed by regular tooth-brushing and mouth-washing after each meal to prevent any hungry Lunatics climbing up Igor's little teeth. Igor had the obligation to visit his hospital at regular intervals and to report to his doctor as any conscientious soldier does. He was always accompanied by Vladimir in his role of main assistant and entertainer. A woman, commonly called "sister" (nurse) waited for us in the hospital but it was beyond Igor's grasp whose "sister" she was! Nor could he understand what "a blood picture" was but now he knew that doctors collect a couple of drops; he said "a little bit of blood from the finger tip". The said drops were shot, blown up, put in fine frames and hung against walls so as to discern the possible hiding places and arms of the Lunatics. The doctor analysed Igor's blood-picture and defined the kind of weapon to be used in action. Once it happened that the nurse told Igor he had a low leukocyte count but the statement greatly confused him. I had to explain him that there is blood streaming along his veins (he is already familiar with the fact). The blood contains tiny, white particles-leukocytes that are in fact, his defence force against the Lunatics from L.A. In the case of some fighters, you have to wait for an increased number so that you can enforce and arm them accordingly. The army sometimes gets tired and becomes sleepy. Having been injected into the spot of the greatest force - Igor's arm muscle - the magic potion swung into action again. At that very moment, the army was awake and armed, first of all, with courage. The powerful liquid remedy is very expensive and some other warriors are in lack of it, so we tried to provide it for some other fearless kids as well.

Igor did not have any idea about haemoglobin but now he knew that everybody's blood contains a little amount of iron, the stronger it is, the more powerful the muscles are. Igor turned into a real veteran of the war against Lunatics from L.A.

15th January, 1995.

Christmas and New Year came and Santa Claus sneaked into the kids' room bringing presents. The Christmas parcel included a whole host of things: books, crayons, puzzles, sweets, plane and helicopter models, not ordinary ones, but battery-operated, with whirling propellers. It seemed that Santa Claus had not received his monthly allowance yet since he did not include any batteries; we applied ourselves to the task of finding all the left-over batteries in our home, checking all the clocks. As a result, all the aircraft moved around, done to death. It was quite clear that Santa Claus had heard about our bitter war and decided to contribute the armament. The children were presented with bows and arrows as it was the only weapon they did not possess. It took them a couple of days to practice arrow-shooting so Dad and I crawled

around our home trying to avoid every possibility of being hit (our foreheads made suitable targets).

At the same time we experienced a little inconvenience because Vladimir and Dad got ill, so we sent them to Grandma and Grandpa to be cared for. Vladimir was delighted with the situation; finally it was his turn to complain; hence he had to be submitted for a medical check-up as well. However, he was bitterly disappointed that he had been rewarded with a kind of a syrup instead of bombs. At that stage, Igor explained to him very professionally that syrup is to be consumed by the sick, and the bombs are given to those that are at war with the Lunatics.

Once it happened that Igor put a question about his attending the hospital although he was not ill! I explained to him that a hospital is not meant solely for the sick, but for the healthy as well. For instance, mothers-to-be stay at a hospital when they get a baby; they do not go to a supermarket, but to a hospital and newborn healthy babies are given also a medical check-up. What is more, Igor and Vladimir attended the same hospital when they were born, despite the fact that they were completely healthy children. Thus the issue was settled and Igor was rarely confused now.

He still visited his hospital at regular intervals, performing the task quite professionally and dutifully. So far he had become acquainted with many new things and he was fairly proficient with medical terms. Sometimes he really surprised me with his knowledge and the way he took things. He became very choosy: he liked to select by himself the vein where a nurse was to attach "a sword". The "sword" had to be black and he got rather annoyed if the action was performed by an aged or poorly dolled-up sister. He was used to addressing them as "sister" (nurse) and did not ask any more whose sister she was. Admittedly it was a very strange hospital; the physicians kept on giving the children sweets and toys. Igor and Vladimir got very nice plush -made horses and simply held on to them. They adored animals and in their games Igor always acted the father-lion, since it is the bravest animal, and Vladimir, being a younger brother, satisfied himself with the role of a baby-lion. On one occasion Igor burst into tears in hospital and I told him lions never behave like that; hares behave like that. He got very offended and he has been trying eagerly not to be a hare ever since. He knew perfectly well that his Lunatics could hardly wait to see him be a coward, because then they could do anything that pleased them; conversely, when they felt his courage, they got very scared and vulnerable. During his stay in hospital, Igor made friends with many children but his favorite fellow-friend was a little boy named Fortunates who had neither a Mom nor a Dad, not even a home so that he had to stay in hospital. We always brought him something nice and it was a real pleasure to

watch the two of them play. Igor was even happier because he managed to make Fortunates laugh. Igor understood vaguely that he was a very happy child since he had all of us around him and I got the impression that he had become even more obedient than usual. Vladimir was still very little and he did not pay attention to all of that. He thought there were not enough of us and kept inquiring about guests.

24th February, 1995.

One morning, on arriving at the hospital, we got a big surprise. We were welcomed by an extremely beautiful lady, so that Dad's and Igor's eyes nearly popped out of their heads. The name of the beautiful lady was Sister Beba and it was love at first sight between her and Igor. At that very point Igor's joy started and my and Dad's trouble. The above named sister fell so much in love with Igor that she kept on kissing him, consequently leaving visible traces of lipstick all over his cheeks; it resulted in the widespread jealousy of the whole male population within the hospital. There were many others who would have liked a little bit of Beba's lipstick on their cheeks but, of course, that possibility was out of the question. Vladimir was the only one to enjoy the privilege and he just posed so sister Beba couldn't miss his cheeks. Our troubles started at the point when sister Beba prohibited any kind of scolding. As a result, our own son started reprimanding us for any trifle that therefore resulted in a severe objection from Beba's side. Having been of the opinion that his culinary wishes were not being fully respected, he even started grumbling about the cooking. Consequently our relations were rather strained and I could smell a war. As for the battle with the Lunatics, it was quite OK. The doctor kept strictly to her strategy. It happened on two further occasions that Igor's army was asleep, but we repeated the procedure with a magic drink and everything was under control. It appeared that the Lunatics were really a secondary problem. The real problem appeared with Igor's belief that he could do anything because he was under Beba's protection; his doctor was unwilling to make any objections either. He was just praised, cuddled and cared for and he availed himself of the opportunity to be most important one. For days Dad and I developed a strategy on how to make him come down to the earth; unfortunately, it seemed it was not going to be an easy task.

The good thing was that Igor was no longer afraid of needles, syringes and the rest of the stuff that even we elderly ones do not like. Thanks to sister Beba, Igor learned how to prepare a shot, needle, cotton-pad and his vein for the "sword". Sister Beba attached the sword and he himself injected the mixture. He even managed to remove the sword from his vein with a smile; so far, unheard of. Sister Beba advised him to learn all these things, so that one day when he grew up, he could come to the hospital and help other children expel

their Lunatics. Igor prided himself had very much, showing off constantly with the things he learned; only a few believed him. Grandmas and Grandpas just rolled their eyes in astonishment and we tried to persuade them it was not just a tale of his own.

4th April, 1995.

At the very beginning of the "our war", Igor started shedding his babyish hair, expecting a real manly hair to grow in a couple of months. A couple of years ago, when Dad and I had a German shepherd dog, we experienced the situation of shedding of fur. We told the children a story about our collecting the fur for many days, all over our home. To avoid a similar situation, we called our friend Maja to trim the children's hair. Maja has magic scissors that do not pull out hair and children like them very much. Once the trimming was finished, we concluded that our children were much like escaped prisoners. A couple of days later, Igor lost all the remains of his babyish hair; he was very satisfied that for some time he need not bother himself with washing and drying. By custom, Vladimir was dissatisfied that he had more hair, and kept on asking why we cut Igor's hair overnight, but not his. He thought we had cut Igor's hair overnight, while he was sleeping, because he noticed his hair was growing, contrary to Igor's.

Presently, Igor was hairless and a cap was an unavoidable garment. A couple of days earlier, Igor and Vladimir had been playing with some other children in a park when suddenly his cap fell off his head.

The children gave him a strange look and an older boy shouted mockingly: "Hey, you bald guy!" Igor was confused and neither he nor I reacted. The game continued and no more attention was paid to Igor's head. When we came back home, he complained to his Grandpa, who himself had been hairless for a long time, and he explained to him that the only thing that matters is what one has inside one's head, not on it! At the same time, he told Igor, in case it happened again, to say: "Hey beardless!". The remark was quite an acceptable one, since neither hairlessness nor beardlessness is an oath. Igor was fairly satisfied both with answer and the instruction.

August, 1995.

Igor won the first and the most important victory in this terrible war. The doctor permitted a deserved break and we could hardly wait to leave the city. It was only when we arrived in other surroundings and met people who hadn't a clue about the terrible battle that was being fought in our family, that we realized how much effort we had engaged in the war against the Lunatics; we had forgotten the little, common, everyday pleasures such as sitting in a coffee-bar, window-shopping and wishing for something not necessarily connected with the war against the Lunatics. Despite this great victory, Igor still had to face a long road ahead of him, leading to the final victory. We believed he had the power to overcome all temptations awaiting for him on this long route. He enjoyed all our support and whether we liked it or not, he was still the GENERAL and we were his ADJUTANTS.

*Irina Cepinac Ban
Belgrade*



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is available in many
languages.**

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Meditation on Impending Death

We place so much importance on life and death these days. Just look how much effort we put into medical research and the constant quest for longer life. Our ancestors, who lived shorter and much more precarious lives, would be astonished at our modern day triumphs of science. For them, death was perhaps more of an everyday reality; awesome, but common enough to treat it matter-of-factly.

I'm not questioning the gift of life. On the contrary, I have learnt it is precious, valuable and not a minute of it should be wasted. It is so fragile. But death holds such horror nowadays that few people ever confront their own mortality and barely think of it. In our enlightened society, it is a greater taboo than sex and it has become a guaranteed conversation stopper.

People are so uncomfortable with death. Look at the euphemisms and words used to avoid it, for example. But why? It's the one thing we all have in common – we are all born to die – oughtn't we be able to share our hopes and fears about it?

I think the reason may be that it is the greatest mystery of all times. Is there life after death? The fear exists because nobody has any firm answers, only guesses. Perhaps it should stay a mystery, to foster in us a healthy regard for life's joys and make us use it wisely.

However it is not that simple. We have been given a few clues and perhaps there are more choices if we look for them. I sometimes despair that death is merely an oblivion until I think of a beautiful sunset, an act of incredible kindness or some moving music, art or poetry and then I can't help feeling that there has to be something that inspires such things. Then I begin to feel that if these are only hints of what is to come then the afterlife must be pretty wonderful!

So my theory is this: death itself is probably just a means of making us value life, otherwise as Hamlet said "we'd all top ourselves tomorrow to get to heaven more quickly". Life and death are therefore simply rites of passage, like marriage or confirmation. They are preparatory stages on a path to a fuller existence and hopefully greater happiness. I feel we should try to see them as a means of furthering our development and a source of opportunity for achieving good.

This is how I have tried to look upon my illness and death, though it certainly has been harder than anything I imagined. Yes, I would have liked to have done a bit more in this life, but who's to say I haven't been saved a few mistakes and done more good than if had I reached the ripe old age of 123! I am thankful to have been spared the slow decline into old age. Maybe I'll have more fun in heaven than I would have had here on earth. Maybe, in that mysterious magical place, I will be able to read all the books written by mankind, see all the places I have never seen and be re-united with old friends and relatives whom I've missed. I might even find the answers to some of the world's puzzles, such as what Great Aunt Dorothea was really like.

My greatest hope is that I can make amends for wrongdoings and that back here you will not grieve too much. However, these are things that I shall have to place in the hands of one greater than I can imagine; I trust He knows best. There has been so much good in all this that I can only begin to thank Him and you for all you have done for me in so many ways.

Death is frightening, sad, terrifying and awful. But it can also be exciting, fascinating, beautiful and even funny! If you can't be thankful for anything else, just think that at least I am going to get there and know the answer to the biggest question in humanity before any of you. Aren't I lucky?

*Eleanor Green
(aged 17, who died of leukaemia)*

Personal Experiences



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The Fifth Anniversary of the NGO “Children and Parents Against Cancer”

On May 18th 2003 the Regional Non-Government Organization “Children and Parents Against Cancer” (St Petersburg, Russia) celebrated its fifth anniversary.

The celebration took place in the City Hall of the St Petersburg Association of Non-Government Organizations of Parents with sick children. There were about 50 people present.

Parents and children decorated the hall with bright balloons. Many people brought flowers. On the walls we fixed big photos and bright hearts showing the most important events in the “history” of our Organization.

It is a good tradition to give presents on birthdays. So the Organization presented to our most active members photo albums with pictures of the most interesting events that took place during these five years.

Parents made toasts to the health of all our children and to the future well-being and success of our Organization. One by one they stood up and pointed out that our Organization plays an extremely important role in their lives, that moral, psychological and material support of the Organization for families with children with cancer are their most precious moments, helping them and their families to return to normal, ordinary life.

Many parents said words of praise for the editorial group of our newspaper “Zdravstvuyte(“Hello!”). The participants of the celebration birthday party thanked the editor-in chief, Elena Astashkevitch, for her excellent work with a big storm of applause.

All the parents and children expressed their deep and sincere gratitude to Katerina Kisseleva, Executive Director of the NGO “Children and Parents

Against Cancer” and congratulated her on such a wonderful birthday. Everybody estimated extremely high her dedication to the Organization, devotion to cancer children’s interests, hard and excellent, highly professional work and sincere attention to the really serious problems of cancer children’s families.

During the birthday party we had plenty of games and jokes; everybody laughed heartily. Elena Astashkevitch, who led the party, invented a nice game: she threw a balloon to the children one by one and they stood up and said tender, precious words to their mothers. It was an extremely touching moment: girls and boys could hardly wait for their turn, the children were so eager to express their love and gratitude to their mothers.

On that day one of the boys, Alick Ibragimov, also celebrated his birthday, so everybody applauded him and he received a nice present: a book about the history of Russia.

All the participants were so happy to meet each other and they talked about their joint trips, sightseeing tours and performances. They spoke about their common friends, looked through numerous photos and enjoyed themselves immensely.

As a “dessert” there was a small concert. Nikita Semenov sang several popular songs, himself playing a guitar. All the audience sang together with him. We would like to express our deep gratitude to the company “Chupa-Chups” for the packs of sweet candy they presented to children. We also want to sincerely thank the meat company “Strelets” for that tasty food they shared with us on our birthday.

*Katarina Kisseleva
“Children and parents Against Cancer”
St. Petersburg*

Sophia's Children

Sarah Wong

Published by: Duo / Duo, Rotterdam

duoduo@xs4all.nl

ISBN 90-72971-70-1

2003 The Netherlands

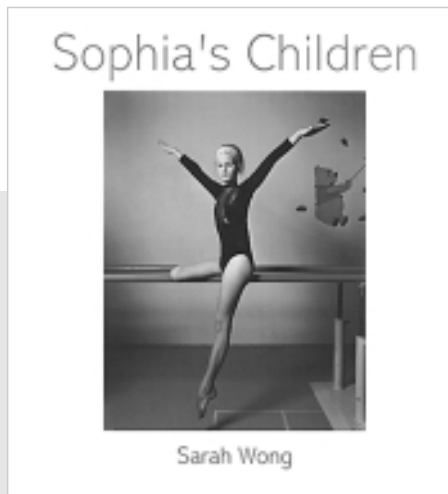
Recently in The Netherlands a most beautiful book has been published: *Sophia's Children*, a photo book with text in Dutch and English.

Photographer Sarah Wong walked for more than two years with her camera and other equipment through the Sophia Children's Hospital in Rotterdam. Other people who see the hospital from the inside have a function: they are doctors, nurses, psychologists, play therapists. Their function opens the gateway to intimacy. Sarah had no function, she was merely a photographer. She had to create her own role and so she did by waiting patiently until the children gave her a role.

The children took the opportunity to express themselves in front of the camera. It gave them back the control over their own world, to show their strength and beauty, despite the circumstances.

Sarah: "The everyday reality of the Sophia Hospital is surreal and had an enormous impact on me: the doctor on a scooter along the corridors or children upside down above the bed, tied up with their drip holder, a child pinching the doctor's nose. It was a new world for me. And hopefully also for people looking at this book of photographs. The children in the Sophia are my star actors within a futurist world of pipes and racing cars. They proudly show off their plasters and drips as if there was nothing wrong. I am very proud of them and the faith they put in me by posing for me."

Marianne Naafs-Wilstra



7th Austrian Symposium on Pediatric Nursing

10 Years of Home Care Oncological Nursing in Vienna

Home care nursing for children and young adults with cancer



Call for Papers

The 7th Austrian Symposium on Pediatric Nursing will be held in Vienna on 15/16 April, 2004. The focus is on home care nursing programs for children and young adults with cancer, the topic honoring the tenth anniversary of the Vienna-based home care oncological nursing service. The symposium organizers are the Kinder-Krebs-Hilfe – Elterninitiative für krebskranke Kinder (a parent initiative supporting children with cancer) and the Berufsverband Kinderkrankenpflege Österreich (Austrian Association of Pediatric Nurses).

The aims of the symposium are 1. to share international experiences concerning home care nursing of young patients with cancer (or any other serious or chronic medical condition), and 2. to draw out perspectives for the future.

We'd like to invite you to submit proposals for papers on any of the following topics, in the context of home care nursing of children and young adults with cancer or similarly severe medical conditions:

- the advantages and disadvantages, from the perspective of the patients, their siblings and their parents.
- the constraints and opportunities, from the perspective of physicians, nursing staff, psychologists and therapists.
- the constraints and opportunities for palliative care at home of children and young adults.
- models for financing innovative approaches to home care nursing.
- case management and coordination in pediatric oncology.
- the specific professional demands placed on physicians, nursing staff, psychologists and therapists.

- supporting home care by giving parents responsibility for nursing- and treatment-related tasks (e.g. catheter care)
- overcoming the problem of large distances between home and hospital; opportunities and constraints for external care teams
- health economics.
- health policy aspects; national and international perspectives.

Abstracts should be between 1,000 and 1,500 characters in length (equivalent to about 15-25 lines) and the submission deadline is 15th September, 2003. Where possible, please submit via email to office@kinderkrankenpflege.at and be sure to include a short bio, plus your address, telephone and fax number. Submissions by fax or normal mail should go to "Berufsverband Kinderkrankenpflege Österreich BKKÖ", Postfach 35, 1097 Vienna, Austria, Fax +43-1-479 64 00).

We will let you know whether your paper has been accepted by mid October, 2003.

With best regards,
Maria Jesse, President

Berufsverband Kinderkrankenpflege Österreich
Fritz Hausjell, Deputy Director.
Kinder-Krebs-Hilfe – Elterninitiative für krebskranke Kinder
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Announcements

Programme for ICCCP0 Meeting – Barretstown 3rd – 5th October 2003

Version 2b – 27th June 2003

Thursday 2nd Oct

Afternoon Parents and survivors arrive, register, settle in
18h00 – 21h00

“Meet and Greet” session

Friday 3rd Oct

Session 1 09h00 – 10h30

Convenor: Julian Cutland, Chairperson: Julian Cutland?

Time	Speaker	Title
5 m	Julian Cutland	Welcome from Conference Chair
5 m	Terry Dignan / AN.Other	Welcome from Barretstown
5 m	Marianne Naafs-Wilstra	Welcome from ICCCP0
25 m	Dan Mornar & Kell May (Canada)	A Patient / Parent Advocacy Program in a Paediatric Oncology Centre: 4 Years Later
25m	Sadie Cutland (South Africa)	Organising a volunteer programme
25 m	Jill Gerke (Canada)	Topic to be advised

Welcome and Opening

10h30 – 11h00

Coffee Break

Session 2 11h00 – 12h30

Convenor: Julian Cutland, Chairperson: Simon Lala

Time	Speaker	Title
15 m	Ms I. Soelistyo (Indonesia)	The Development of the Parents Organisation in Jakarta
15 m	Katerina Kisseleva (St Petersburg, Russia)	Social Defence of Cancer Children in Saint-Petersburg. The Position of The Parents Organization within the Social Structure of the City
15 m	Mi Ok Cho (Korea)	One on One: Volunteer Tutor Program to Help a Child Adjust to School Life While Recovering
15 m	Marina Novitskaya (Ukraine)	Art and handicrafts made by hands of children with cancer: emotional therapy and real future prospect.
15 m	Elfi Schattauer (Austria)	E-Learning as a Motivation for Adolescents and Young Adults with Cancer - “European Computer Driving Licence – ECDL”
15 m		Space for one more talk here

Parent Groups – Development and Programmes

12h30 – 13h30

Lunch Break

Session 3 13h30 – 15h00

Convenor: Mark Chesler, Chairperson: Mark Chesler

Time	Speaker	Title
	Mark Chesler	TBA
	Aaradhna Mittal (India)	TBA
	Workshops	

Group Development and Building Sustainability

15h00 – 15h30

Coffee Break

Session 4 15h30 – 17h30

Convenor: Julian Cutland, Chairperson: Edith or Ira

Time	Speaker	Title
20 m	Geoff Thaxter (UK) & ANO (CR-UK)	ICCD – 2003 feedback, and introduction to ICCD 2004
20 m	Christine Wandzura	Fund Raising – the gospel according to Christine
5 m	Charles Langhorne (UK) - maybe	Cow Parades
45 m	Workshops	ICCD; Cow Parades?; Business Plans / PR?
19h00-onwards		Irish Pub Night – Barretstown Hall – Irish music, etc. (with food and good ale)

Fund-Raising, Marketing, PR

Announcements

Saturday 4th Oct

Session 5 09h00 – 10h30

Keynotes - Late Effects, Quality of Life and Bereavement

Convenor: TBA, Chairperson: Ira or Edith

Time	Speaker	Title
30 m	Christine Eiser (UK)	Quality of life during and after treatment for childhood cancer – psychological aspects
30 m	Mike Stevens (UK)	Late effects – current medical developments
30 m	Peter Hanlon (Ireland)	- to be confirmed Aspects of bereavement – to be confirmed

10h30 – 11h00

Coffee Break

Session 6 11h00 – 12h30

Supportive and Recreational Therapy

Convenor: Christine Wandzura, Chairperson: Christine Wandzura

Time	Speaker	Title
	TBA by Chris	TBA by Chris

12h30 – 13h30

Lunch Break

Session 7 13h30 – 16h15

Interactive Board Meeting and AGA

Chairperson: Marianne Naafs-Wilstra

Time	Speaker	Title
90 m		Interactive Board Meeting – presentation & discussion of plans by ExCo
15 m		Short coffee & comfort Break
60 m		Annual General Assembly

16h30 – 18h30

New Board to meet, and also to have time with the Norwegian parents.

Others to have time off to explore local surroundings or take part in the Barretstown activities.

19h00 - lateICCCPO Annual Dinner and Cultural Evening at Barretstown

Sunday 5th Oct

Session 8: 09h00 – 10h30: Workshops – Childhood Cancer in Developed and Developing Countries

Convenors: as below, Chairpersons: as below

Time	Organisers	Title
1h 30m	Gerlind/Simon/Chris	Childhood Cancer in Developed Countries – problems, approaches, solutions
1h 30m	Sadie/Ira/Edith	Childhood Cancer in Developing Countries – problems, approaches, solutions

Session 9 10h30 – 11h00

Closing

Convenor: Board, Chairperson: Simon Lala

Time	Speaker	Title
5 m	Chris or Gerlind?	Feedback on Developed Countries Workshop
5 m	Ira or Edith?	Feedback on Developing Countries Workshop
10 m	Anthony Penn/Mark Chesler	Feedback from Survivors Sessions
10 m	Simon Lala	Review and Closing

11h00 Departure for the airport, etc

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Looking for a book on childhood cancer in a specific language?

Simply contact the

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To update the bibliography, please send your books, newsletters, pamphlets, any special videos or other publications that your organization produces to Kids Cancer Care. Include (in English!) a brief outline about the content of those materials. All materials will be included in the next issue of the international bibliography (which can also be found on the website: www.icccpo.org).