

**ICCCPO Newsletter**

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**Editorial Staff:**

Gerlind Bode  
Pia Bonini  
Sue Grant  
Marianne Naafs-  
Wilstra  
Jacqueline Costelloe

**Address of Secretariat:**

International  
Confederation of  
Childhood Cancer  
Parent Organizations,  
c/o VOKK,  
Schouwstede 2d  
3431 JB Nieuwegein, NL  
tel: +31 (30) 2422944  
fax: +31 (30) 2422945

**Bank Account:**

CenE Bankiers  
Postbus 85100  
3508 AC Utrecht  
Netherlands

**Dollar account 16128**

BIC: CEBUNL2U  
IBAN: NL09 CEBU  
0000 0161 28

**Euro account**

699211875  
BIC: CEBUNL2U  
IBAN: NL49 CEBU  
0699 2118 75

Si preferien recibir  
este boletín en la  
edición en castellano,  
por favore porganse  
en contacto con la  
Secretaría de ICCCP  
en Hollanda.

## Notes from the editors

Though we are working on this winter issue of the ICCCP news in December 2003, it will not reach you before the New Year has started. Nevertheless, we would like to send you all our best wishes for the year 2004 – may it be a good one for you all!

This issue includes some of the talks presented at the most recent General Assembly in Barretstown, Ireland. We are trying to get as many of these presentations as possible to be published (here and on the website). It was again a very intensive and educational meeting with a full program for parents and for survivors (who joined us for the third time). The survivors have given themselves a structure and a mission statement and have plans for the future (s. p. 8).

More than one hundred guests attended this year's meeting, representing over 30 countries. The venue (the Barretstown Castle Gang Camp)



was for all participants a very interesting place to visit and the hospitality of the "Barretstown Gang" could not be topped! We all felt very warmly welcomed and well taken care of and learned much about the camp program offered here. Special thanks go to the chef cook and his kitchen team who were able to meet all needs and tastes within no time.

Early along in 2003 the board had decided to separate the annual ICCCP meeting from the SIOP conference which took place in Cairo as the board felt uncertain about the whole conference with respect to the then still ongoing war in Iraque. Barretstown seemed to have been a very good choice as it offered all the necessities for the meeting and a possibility for vivid exchange and contact among the participants as they all stayed on the compound for the entire time of the conference. Of course, we missed the exchange with other professionals in pediatric oncology, such as physicians, nurses, psychologists. This will be possible again in Oslo (Norway).

The General Assembly admitted 9 new member organizations, (8 full, 1 associate) from: Armenia, Bosnia Hercegovina, China (Hong Kong), Czech Republic, Korea, Paraguay, Russia (3 organisations), which means



## Contents

<b>Notes from the editors</b>	<b>1</b>
<b>Announcements</b>	<b>2</b>
<b>International Childhood Cancer Day 2004</b>	<b>3</b>
<b>Long-term follow-up</b>	<b>4</b>
<b>Rehabilitation from childhood cancer</b>	<b>6</b>
<b>ICCCPO-survivors' group</b>	<b>8</b>
<b>E-Learning for patients</b>	<b>10</b>
<b>How can parents help themselves?</b>	<b>12</b>
<b>Books</b>	<b>15</b>
<b>Executive Committee</b>	<b>16</b>



ICCCPO includes now 65 member organizations from 52 different countries. We can be very proud about this development. And we can be very proud about the fact that we will be looking back on ten years of existing this coming Spring. There will be an official

commencement in May in Spain along with a symposium by the Spanish confederation which initiated the inauguration of ICCPO in 1994. And there are plans for celebrating these ten years along with the upcoming AGA meeting in Oslo, which again will be in conjunction with the SIOP meeting there.

**The ICCPO board has changed as follows:**

Marianne Naafs-Wilstra who served for 4 years as president stepped back from this position and Simon Lala (New Zealand) was elected chairman. Geoff Thaxter (UK) became vice chair and new member to the board is Irina Ban (Serbia) on the position of David Orren (Israel) who resigned. You will find the new list on the back of the newsletter.



Note that there will again be a celebration of the **International Childhood Cancer Day (ICCD)** on February 15th 2004 (more on the following page).

We wish you all a very good start into the New Year!  
*The newsletter-team*



**Announcements**

**27 - 29 May 2004**

**International Meeting in Valencia**

Organized by ASPANION

With a program for parents and psychosocial staff on May 29.

On May 27 and 28 there will be the official Ten-Year-Celebration with a reception in the Town Hall and some other activities. For more detailed information please contact:

ASPANION

Plaza Pablo Picasso, 9-3°D

46015 Valencia

Tel. +34 963 47-1300 / Fax: +34 963 48-2754

Email: [aspanion@ctv.es](mailto:aspanion@ctv.es)

**25 - 28 August 2004**

**7th World Congress of Psycho-Oncology in Copenhagen**

theme: "Understanding Diversities – Development of Strategies for Psychosocial Oncology"

hosted by the International Psychology Society

For more information visit: [www.ipos2004.dk](http://www.ipos2004.dk)

**16 - 19 September 2004**

**36th Congress of International Society of Paediatric Oncology SIOP 2004, in Oslo, Norway**

For more information please contact:

Congrex Holland BV

P.O. Box 302

1000 Amsterdam,

The Netherlands

[www.congrex.nl](http://www.congrex.nl)

[www.siop.nl](http://www.siop.nl)



**ICCCPO General Assembly**

A parent program as well as a program for survivors will be organized along with the SIOP meeting.

More details will follow later.

Please visit also the website: [www.icccpo.org](http://www.icccpo.org)

**26 - 28 February 2004**

**3rd SIOP-Asia Conference Dhaka, Bangladesh**

"Childhood Cancers is curable – Let's build on our past"

with a special program for parents

For more information contact:

[ashic@citechco.net](mailto:ashic@citechco.net) or [class@globalctg.net](mailto:class@globalctg.net)

# CANCER RESEARCH UK JOINS WORLDWIDE CAMPAIGN TO HELP CHILDREN WITH CANCER

CANCER Research UK will again unite with parents from 41 countries on February 15, 2004, to support the third International Childhood Cancer Day.

The aim of the day is to help children with cancer get the best possible treatment and care, no matter where they live in the world, by raising both awareness and money.

As support for the day grows, the organiser, The International Confederation of Childhood Cancer Parent Organisations (ICCCPO), is sure it will be even more successful than the last two years and raise more vital funds for the 250,000 children around the world who develop cancer every year.

Professor Alex Markham, Chief Executive of Cancer Research UK, says: "We are delighted to support International Childhood Cancer Day – such an important and unique annual event.

"We are committed to working on global initiatives and keen to do everything we possibly can to help the thousands of children around the world who have cancer. Every single one of these children deserves adequate treatment and care, no matter where they live and International Childhood Cancer Day is a fantastic way of raising awareness about this, along with vital funds.

"As a father myself I know how precious children are, so I urge everyone to support the day to help children with cancer all over the world."

Marianne Naafs-Wilstra, Chair of ICCCP, says: "We are delighted with the support and involvement for the third International Childhood Cancer Day.

There is a great need for basic access to treatment, emotional support and long term help and this special day enables organisations to provide for these needs."

Geoffrey Thaxter, ICCD co-ordinator, says: "After the success of two previous International Childhood Cancer Days, everyone is fired up for the challenge of raising more funds, more awareness and having more fun with the aim of helping thousands of children around the world."

If you would like to find out how you or your organisation can get involved with ICCD 2004, please contact Geoffrey Thaxter on 01737 555411 or email [info@lisathaxter.org](mailto:info@lisathaxter.org).

The International Confederation of Childhood Cancer Parent Organisations (ICCCPO) was founded in Spain in 1994. It has 56 member organisations in 46 countries.

ICCD is taking place in the following countries:

Argentina · Egypt · Italy · Portugal · Australia · France · Japan · Romania · Austria · Finland · Latvia · Russia · Bangladesh · Germany · Lithuania · South Africa · Brazil · Greece · Luxembourg · Spain · Bulgaria · Iceland · Malawi · Sweden · Canada · India · Mexico · Switzerland · Columbia · Indonesia · Morocco · UK · Croatia · Iran · Netherlands · Ukraine · Cuba · Ireland · New Zealand · USA · Denmark · Israel · Nicaragua · Venezuela · Norway · Yugoslavia.



**A new translation of the Robby Radio into French:**

## **Robby Radio Lutte contre les méchantes cellules cancéreuses**

The booklet can be ordered from the Swiss group:  
Kinderkrebshilfe Schweiz  
Sonnenrain 4, 4534 Flumenthal, Switzerland  
[www.kinderkrebshilfe.ch](http://www.kinderkrebshilfe.ch)

**Visit our website to find your language.**

**[www.icccpo.org](http://www.icccpo.org)**



# LONG-TERM FOLLOW-UP

Paper presented at the ICCCP0 Conference, Barretstown (Oct. 2003)



Being asked to talk about long-term effects of childhood cancer raises a number of conflicting emotions. On the one hand, it is an indication of the success associated with treatment that we are now able to ask questions about the long-term impact. On the other hand, the disappointing thing is that the long-term effects identified are inevitably associated with compromised quality of life (QOL). Until such a time when it is possible to treat childhood cancer without any adverse consequences, it is essential to identify the kind of late-effects that are likely to occur. In this way, families and children can be prepared for the future, and that knowledge may in itself result in a reduced impact.

I want to begin by echoing some of the things that Mike has said. It is especially daunting to talk to an audience like you. I recognise that as parents you have much greater experience in looking after a child with cancer than I or any other researchers can ever have. For that reason, I am really pleased to have the opportunity to talk to you, because it is vital that research answers the kind of questions that you think are important. Research has to be judged by the users. In practice I work in a university department and my work tends to be judged in terms of published papers. For myself, I would like the work to be seen to be of value to children, parents, teachers and everyone else involved in looking after these children.

I was asked to talk about the long-term or late effects of cancer and its treatment. Mike has already described some of the physical effects that can follow from specific treatments. I am going to describe some of the work we have done looking at the more educational and psychological late-effects. I would like to acknowledge the contribution of Cancer Research UK to this, as they have funded this work for the last 10 years. The goals of treatment are to achieve a healthy well functioning individual, and that means that it is important from diagnosis to work toward realising children's potential.

Having said all of that, it is very natural that parents should worry about their child's general development. We hear a lot about how experiences during childhood have implications for functioning in later life. For example, it is well established that children who live in deprived circumstances grow up with fewer educational achievements as well as social skills. Certainly children treated for cancer have many disadvantages. They experience aggressive treatment,

multiple hospital appointments, needles and other procedures. School absences are likely to have negative implications both for academic achievement and social relationships. If a child is away from school for any length of time, they miss out on making friends, and can often feel "different" and "left out". Although it is obvious that these children potentially experience many problems and disadvantages, they are usually very young on diagnosis, and for that reason we can hope that they forget about many aspects of treatment.

As part of our work, we have talked to lots of parents about their children, asking their views about the effects of treatments. Parents describe their children in the same way as any parent describes their child. They can be loveable, adorable, but also a pain in the neck. What parents of a child with cancer also say is that these children become "old before their time", "like a little old man", "went into hospital a child and came out a man". It is often said that children get on less well with other children their age but better with adults, they lack confidence, they forget things, but also that they are very caring.

You may feel that some of these descriptions fit your own child, but there is huge variability and it is not possible to describe any single way in which children react. One of the big difficulties for everyone is deciding how far any problem is related to cancer or just part of normal growing up.

For a number of reasons it is normally recommended that children treated for cancer should be followed up after the end of treatment. Follow-up is important for doctors because it enables them to link late-effects with treatment type, so that new treatments can be devised that reduce the probability of late-effects. In addition, information from follow-up clinics can be used to provide information for future families, and for the individual patient they can be useful as sources of information.

Whatever the merits of follow-up, there is a need for balance. Follow up can increase anxiety. As new research becomes available, families can be confronted with distressing information, suggesting that treatments the child received, although vital at the time, have subsequently been shown to be linked with late-effects. An example is the now established link between anthracyclines and cardiac toxicity. Individuals have a right to know about research of this kind, but it is rare that they are able to change their risk as a result of the information. Preoccupation with possible late effects can minimise involvement in normal activities. This is exactly what is not wanted.

Mike has summarised many of the common late-effects in his own talk and so I am not going to discuss the physical problems again.

Instead I want to focus on what is known about the effects of cancer treatment on Learning and employment and social skills.

## Learning and Employment

I don't need to tell you that children typically have a lot of time off school, especially in the year after diagnosis. There are lots of reasons for this, but infections, hospital appointments, and just feeling tired are the most common. Sometimes, families become so fearful that the child may get an infection that they keep them off school just in case. Inevitably, school absence has a big impact on school work and eventually on exam success.

If you compare a group of children treated for cancer with others of a similar age, you generally find that they have lower IQ scores and achievements like reading and arithmetic. The extent of the problem or the risks of underachievement is greater for those treated with brain irradiation, and for those who were younger on diagnosis. Disappointingly, children's scores can decrease with time since diagnosis. This means that they drop behind following diagnosis but they do not catch up after treatment ends.

Almost all children with cancer are therefore at risk in terms of their education, and need a degree of special help to succeed in the school system. It has been suggested that almost 50% of those treated for a brain tumour have special educational needs.

There are of course implications for work and employment. Children treated for cancer are more likely to be unemployed than their brothers or sisters, and again those treated with cranial irradiation face special difficulties.

In some of our own work, we have shown that the experience of cancer does not only affect the likelihood of employment, but also affects an individual's choice of work. We studied a group of survivors who had previously been treated for a bone tumour and asked them how their experiences had affected their choice of work. Ten said it had made no difference. These survivors were often in office based work, involving little physical movement. A further 14 felt their opportunities were restricted. These largely included survivors in manual occupations who felt that their inability to stand or reduced flexibility restricted what they could do. For some these restrictions were on-going. Others anticipated restrictions in the future. For example, one young man was a plumber. Although he was managing the work at the time, he reported that it was hard manual work and he did not expect to be able to keep it up indefinitely. A further eight survivors reported that their illness experience had direct-

ed their choice of work. Through their own experience and watching others, they had all decided to go into the "caring" professions. They were interested in teaching, looking after people with disabilities or training as nurse or doctor. It was not a "good thing" that they had had cancer, but the experience could be turned to advantage.

The second point I want to make is the way cancer can affect an individual's social and emotional life and experience. I reported in the beginning that many parents describe the difficulties their child has relating to other children. School absence, maybe looking different as a result of radiotherapy, can all contribute to children having difficulties making friends.

In addition, there is now some evidence to suggest that a small proportion of children and their parents experience post traumatic stress disorder as a consequence of the disease and treatment. This can take the form of re-experiencing treatment, intrusive thoughts, and extreme anxiety about relapse. Approximately 12% of children and 15% of parents experience PTSD.

It is one thing to describe these consequences of treatment, it is quite another to determine exactly the cause. Difficulties can arise as a direct result of treatment. For example, it does seem clear that many learning problems are a direct consequence of cranial irradiation. But it seems likely that many other causes are involved because it is not the case that all children treated in the same way have the same problems. It is possible therefore that many factors interact with treatment variables to determine the final outcome for any individual child. The reactions of family, friends and teachers are thought to be highly influential. For this reason I want to consider what can be done.

As far as education is concerned, we have to acknowledge that schools have limited resources. They may simply not be able to give the child the kind of individual teaching that would be required to overcome past disadvantage. At the same time, teachers may not have the relevant knowledge. Knowing how to relate to a child who has cancer is not covered in standard teacher training programmes. Like many other people, teachers' knowledge of cancer is often very limited and so they rely on what they know about other illnesses. They know that for the most part children can become ill with a cold or chicken pox, but fairly quickly they are back to normal. They do not understand so well that the child can have cancer but seem perfectly well, or that it is necessary to continue with hospital appointments for a number of years. For this reason, many teachers may initially be very sympathetic but they lose patience and sympathy with time.

Partly in response to this, we are in the process of writing an information leaflet for teachers. The aim is partly to increase general knowledge and dispel some

of the myths associated with childhood cancer. We hope also that greater knowledge will promote greater understanding and empathy.

Undoubtedly children need regular assessments throughout treatment. We do know that children can continue to experience learning problems long after completion of treatment. Parents therefore need to be proactive. It can be hard to get the kind of educational support that the child needs. From this point of view, it may be valuable for parents to share their experiences, and maybe ICCPO could offer a general information service about this.

## Implications

The goals of treatment are to maximise the chances that the child can experience a "normal life", and achievement of this involves collaboration of a range of professionals as well as family and friends. School is very important for children because it is where they learn, not only to read and write but also how to

relate to others, and where they make friends. Minimising school absences has to be essential. In addition, teachers need to feel part of the "team" and this means they need information, not only on diagnosis but throughout treatment. Communication is vital both from the family but also from the hospital.

The message from this talk is therefore that we do need to be aware of how treatment can affect the child's general development. Diagnosis of cancer does not necessarily mean that children will inevitably experience learning and social difficulties, or fail to get satisfying work as adults. However, it does mean that it is more difficult for them than otherwise, and for this reason holistic care needs to include recognition of this, both in the early days of treatment, as well as in the longer term.

*Christine Eiser  
CR-UK Child and Family Research Group,  
University of Sheffield,  
Sheffield, S10 2TP.*

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# Rehabilitation from childhood cancer: a survivor's perspective.

In 1981 I was a 15-year-old and in the fourth form at school. For several months it had become obvious that something was seriously wrong with me. I developed impaired hearing, loss of appetite, constant vomiting after meals and poor co-ordination. Despite a battery of medical tests no doctor could pinpoint the cause. This was very stressful for myself and for my family. I was eventually referred to a neurosurgeon for a brain scan, and was immediately diagnosed with a pineal germinoma brain tumour. Although mine was a very rare type of tumour, it consisted of very primitive cells, which were especially sensitive to radiation therapy. My reaction to the diagnosis, and knowledge that it could be successfully treated with radiotherapy was one of immense relief.

On the road to recovery, I developed a positive philosophical approach. There is strength from knowing that however bad the treatment might be, it cannot be worse than not knowing what was wrong before the diagnosis. Knowing the devil and that it can be defeated, you have won half the battle. The treatment, however awful, is your friend and the medical staff are on your side. Radiation side-effects such as acid saliva, loss of energy, concentration span and hair, and steroid fluid bloating- are all tolerable and less of a source of stress if you know they are part of the big climb out of the pit. The trick is to associate these side effects with self-esteem (braveness, determination) and not to be afraid of them. There is always something to be gained, even in such a com-

promised situation. In accepting that at this point you will be out of commission for a while but have the goal of returning to the mainstream, I found the following "freeway" analogy helpful:

"The freeway is the simplest, fastest, most efficient way to get from one town to another. I want to get to my destination like everyone else, but I can't use the freeway for now. Thus I must use the secondary roads and country lanes which are slower and less efficient. There are two ways to look at the situation: (a) it's a jolly nuisance and I'm going to get terribly upset and frustrated, or (b) the situation provides the opportunity to get a better view of the countryside, visit the small towns along the way and gain a richer experience by the time I get to my destination. As opposed to a screaming rush with snarling traffic, dangerous overtaking and road rage to arrive grumpy and hassled and in which you have gained nothing but a headache!"

Here is the opportunity for a re-discovery of yourself, who you are and the many things that you are still capable of doing. If you can keep your spirits up during cancer treatment, you can handle almost everything else afterwards!

The full support of my family was instrumental in helping me to cope. We have always been a close family and when this crisis occurred everyone pitched in and helped without complaint. My brother, at the same school as myself, was an important liaison

between school and home. This kept me in touch with what was happening there. It is very important to know that your school is there for you to come back to and that they are thinking of you during this socially isolating time. The psychological support of my sisters was also very important. This encouraging home environment instilled an inner strength, which was vital in the difficult years to come.

After the treatment I was left with pituitary hormone deficiency, chronic tiredness, permanent moderately severe hearing loss and minor inco-ordination. One important aspect in returning to school the following year was that I was treated in the same way as others but with recognition of my special needs in certain circumstances. Returning to school was very difficult, as I had not foreseen that I would have remaining difficulties in academic thinking, concentration span and tiredness. Teachers were aware of my situation and were keen to help meet my needs, but I had to be assertive in stating my difficulties first. This resulted in altering my schedule for the first year back. I attended classes as normal but with a reduced workload and the delaying of full assessment and exams for sixth form till the following year. I attended university after six years at school, spreading Stage 1 science papers over two years.

#### **Several tactics were useful in coping at school and university:**

- Firstly, I consistently sat at the front of the classroom or lecture theatre in order to maximize hearing ability. Although this limited conversation with other students (who like to sit as far at the back as possible for social reasons), I had to keep in mind the primary reason I was there! I also was assertive in asking teachers or lecturers to clarify points which I had not heard or understood well.
- Secondly, I organised my day so as to be aware of my tiredness and reduced concentration span. This meant taking regular breaks from study and immediately after lectures. In revising for exams (at school and university) I rewrote written material into chart-flow diagrams to aid memory. This involved recognizing the pattern and sequence of ideas underlying the material. It is always easier to remember a visual pattern or direction than endless notes.

#### **Generally in life, I find the following approaches useful:**

- The first is the concept of assertiveness. Of not being afraid to take on new opportunities and risks as long as I am assertive to others (and myself!) about my limitations and special needs. This means ensuring that I understand the situation I am encountering and what is expected of me and communicating my special needs to others.
- The second approach is the concept of control. As the Chief Executive Officer of Chris Jerram Inc., I have delegated responsibility to various "divisions". One is the Division of Medical Management and is responsible for management of my medical condition (taking medication, monitoring energy level, and reporting anything out of the ordinary).

The Division of Awareness (managed by Hugh Watchitt!) has the task of compensating for my "perceptual delay"- (slow central processing and reaction to sensory input)- for example extra care crossing roads, allowing time to orient to a new situation.

The Division of Critical Analysis is responsible for decision-making- i.e. "is this a good thing for me to be doing", "what am I getting into and how much am I likely to get out of it?". I have to be aware that what is right for other people may not be right for me. There is no shame in making a choice which may not be the most "popular".

- Lastly, there is the Department of Stress Management. I have difficulty dealing with stressful situations at times, and have two main ways of coping. One is to use a system of gears, and to change gear up or down to suit the situation. Recognize when it is inappropriate to roar into top gear with adrenaline pumping when you cannot do anything to make things happen any faster. A second is to compartmentalize a situation and only deal with one compartment at a time. Ignore everything else which is coming at you. Prioritising is important.

Finally, I cannot say enough for the ongoing support of family, school and, in my case the Audiology Department of Auckland University in encouraging the rehabilitating young cancer patient to form a positive view to his or her condition. At the end of the day, he or she will have to accept, monitor and advocate for their condition in their own way, and the role for the parent, sibling, teacher or colleague is to recognize and bolster any steps which the survivor takes towards this end.

*Chris Jerram, New Zealand*

## Our own “Heroes“



Parents devoting their time in self help initiatives for children with cancer are “heroes” per se. There is no question. They do this all over the world. Only, very seldom this is recognized by the media in general. Thus we include this article from the Reader’s Digest Canada magazine on Christine Wandzura, as we feel that more parent group leaders should be recognized for their valuable work. Christine is just one very good example.

The board is proud about its “heroes” and congratulates Christine Wandzura!

### **Reader’s Digest Canada launches annual award to celebrate extraordinary service to others**

Montreal, June 24, 2003 – Reader’s Digest Canada today announced that its Canadian Hero of the Year for 2003 is Christine Wandzura of Calgary, founder of the Kids Cancer Care Foundation of Alberta (KCCFA). An article in the July 2003 issue of Reader’s Digest profiles the magazine’s first Hero of the Year, outlining the story of her work on behalf of children living with cancer. The magazine inaugurated the annual award to celebrate the many Canadians whose heroic efforts make a real difference in their community and in the lives of others.

„I was absolutely shocked when I was told that I would be the first Reader’s Digest Canadian Hero of the Year,” said Christine. „I am truly honoured by this wonderful tribute and I would like to thank those at Reader’s Digest Canada who felt that my efforts are worthy of hero-status. I hope that I can inspire others

to dedicate themselves to a cause or effort and make a difference in their communities.”

Prior to starting the KCCFA, Christine struggled to deal with the loss of her son Derek, who was diagnosed with brain cancer at age five and died four-and-a-half-years later. The summer before losing Derek, Christine had taken her son to a camp in British Columbia for children with cancer and was inspired by her son and the campers who relished every opportunity to play like other kids. Christine felt very strongly that a similar camp should be created in Alberta. After Derek died, she helped the Canadian Cancer Society organize sending 43 kids to a camp in Kananaskis, just west of Calgary. While this was a major step in the right direction, Christine felt that much more could and should be done to help kids in need. With this determination, Christine quit her full-time job to dedicate herself to raising funds for a series of camps for children with cancer throughout Alberta. Christine’s Kids Cancer Camps of Alberta was launched in the summer of 1995 and in 1997 summer day camps in Calgary and Edmonton were established. In 1999, Christine expanded the organization’s mandate to include fundraising for pediatric oncology research and clinical support.

„Christine’s determination to make a difference, her energy and her drive, and the results she achieved are truly inspirational,” said Murray Lewis, editor-in-chief of Reader’s Digest Canada. „She’s an extraordinary person and an example for others. Celebrating and sharing stories like hers is part of what we do at Reader’s Digest and it’s exciting to be able to recognize the heroism that Christine embodies.”

## The ICCCPO Survivors’ Group



The first ICCCPO survivors’ meeting was held in Luxembourg in September 2001. Prior to this, childhood cancer survivors attended the same meeting as the parents and health workers. Although the ICCCPO parents’ meeting was interesting and many of the issues pertinent to us, it was recognised that our needs as survivors differed from those of parents, and with the support of the ICCCPO committee and guidance of Prof. Mark Chesler (Parent of a long term survivor (LTS) of childhood cancer and ICCCPO Board member), the ICCCPO survivors meeting was initiated.

Our intention was to create a forum for survivors from all over the world to share their experiences in a friendly, unthreatening environment. The first meeting focused on sharing individual experiences while undergoing treatment for cancer. We have now evolved into an organisation primarily concerned with issues faced by long-term childhood cancer survivors, and more particularly, long-term survivor groups. This was reflected in two key sessions at the 2003 meeting in Barretstown, Dublin: “Long term follow up of children with cancer”, where we discussed how, where and by whom we would like to be followed up, and “How to set up a cancer survivors group in your own country”. This was the most popular session, and we will continue to focus on this fundamental topic in future meetings. In order to facilitate the aforemen-



tioned sessions, experts in their respective field presented their thoughts on the topics, and we then discussed them in small groups. This again differed from previous meetings at which only survivors and Mark Chesler were present.

Our meetings are not all hard work! We also have a lot of fun. It's a great place to meet new friends and have a good time. Saturday afternoon was spent practising archery and wall climbing, and the Irish Ceili dancing night, though rather tiring, was especially entertaining.

21 survivors and 2 siblings from 14 countries attended the Barretstown 2003 childhood cancer survivors meeting, and the age of survivors ranged from 16 to 29 years. There were representatives from Western and Eastern Europe, North America, New Zealand and Asia. Most survivors were representatives of their own national or regional childhood cancer groups, or were interested in starting up new survivor groups.

Here is our mission statement and goals as defined at the 2003 ICCCPO survivors group meeting:

### Mission Statement

Young adult cancer survivors brought together to share resources and experiences in order to support and develop childhood cancer survivor organisations everywhere in the world.

### Goals of ICCCPO Survivor's Group

Support the implementation and development process of national and local survivor groups.

Establish an international network that provides information and resources for survivor groups.

Connect with relevant professionals to provide information on important issues faced by childhood cancer survivors.

Energise and inspire cancer survivors worldwide.

### The ICCCPO Survivor's Executive Committee

In order to preserve continuity and ensure the success of future meetings, an executive committee has been formed, consisting of six survivors who will be working together to help plan the next meeting in Oslo in 2004. The ICCCPO survivors Committee members:

#### Chairperson: Dr Anthony Penn (UK), Survivor for 16 years

- Previous Executive member of CHOC (South African childhood cancer parents organisation)
- Has been involved in all three ICCCPO survivors meetings
- Medical Doctor at Frenchay Hospital Bristol, UK

#### Vice Chairperson: Prudence Walker (New Zealand), Survivor for 4 years

- President of CanTeen – The New Zealand Teenage Cancer Patients Society
- Studying B.Health Science (Rehabilitation)

#### Secretary: Alex Brownsdon:(UK), for 17 years

- Active member of TOPS (Teenage Oncology Patients Support,UK)
- 2nd ICCCPO survivors meeting
- 3rd year of B.Science in Psychology



#### Communications Liaison: Eva Coenen (Netherlands), Survivor for 9 years

- Actively involved in organising survivor activities in conjunction with VOKK (Dutch Childhood Parent Organisation)
- Has been involved in all three ICCCPO survivors meetings
- 4th year Medical Student

#### ICCCPO Liaison: Nicole Bruton (Canada), Survivor for 20 years

- Active in the Alberta Kids...
- B.Arts (Psychology), Currently studying towards B.Education

#### Developing World Representative: Aditya Soelistyo (Indonesia), Survivor for 5 yrs

- Eager to establish survivor's organisation in Indonesia
- Studying B. Information Technology

### SIOP 2003

The survivors' opinions on long term follow up were presented at the International Society of Paediatric Oncology (SIOP) 2003 Annual Conference in Cairo, in the session: "Long- term follow-up guidelines: Research initiatives in risk-based screening of childhood cancer survivors." The talk was extremely well received, and the response from the doctors present was overwhelming. Doctors and other decision makers are clearly interested in what we, as survivors have to say about our care, which is very encouraging for our future as advocates for childhood cancer survivors all over the world.

### Contact Magazine,

An article detailing the activities of the ICCCPO survivors group will be published in a special international issue of Contact, a magazine for families of children and young people with cancer to coincide with



the International Childhood Cancer Day. on 15th February 2004 The international issue will be translated into several key languages and distributed globally through ICCCPo and SIOP.

### Feedback, Barretstown 2003



Overall we all had a great time, met lots of new people and learnt a lot about how childhood cancer groups work in different countries. Some of the comments made in the feedback questionnaire illustrate this:

"Meeting new people and making friends with other survivors from other countries – gaining multicultural awareness."

"Finding out and sharing experiences – we will be able to use what we have learnt to help others."

"Walking away feeling excited for future survivors."

"Everything was great!"

"This meeting was even better than I expected and I gained a lot from it."

The next ICCCPo survivors meeting will be held in September 2004, in Oslo, Norway, and we are looking forward to continue sharing ideas and experiences with other childhood cancer survivors all around the world.



*Anthony Penn  
Chairperson, the ICCCPo Survivors' group  
antpenn@doctors.org.uk*

## E-learning as motivation for child and young adult cancer patients

### "European Computer Driver's License (ECDL)"

Occupational therapy project for children and young adult cancer patients

Although the healing and recovery process stands in the foreground for the treatment of children and young adults with cancer, the young patients frequently think about the time after the chemotherapy. Questions such as "What about school?" or "What will I do for a living?" occupy the youths and their parents.

#### A driver's license for the PC

With the European Computer Driver's License, we can show our children additional perspectives for the future, which means that this certification training makes the entrance into working life or school easier for young cancer patients after the treatment.

The project "European Computer Driver's License (ECDL)" was started by the psychosocial group of the St. Anna Children's Hospital, the Vienna consulting company „die Berater" and the Kinder-Krebs-Hilfe (Children's Cancer Aid Association) and is subsidized by partner companies, in particular the Austria Computer Association.

Through the networking of the hospital rooms and the provisioning of computers and notebooks, learning instruments are now available which can be used regardless of time, age and prior education.

The youths profit in many additional ways from this project: They have meaningful activities during their therapies, they are distracted from their difficult situ-

ation, they are given the feeling of learning something valuable for the time after the illness and discover better contact with others in their situation through the course.

A major difficulty was initially presented by the non-homogeneous group: "Age differences, prior education as well as unforeseeable pauses due to varying chemotherapy durations make "normal" instruction nearly impossible".

Because most of the patients must be treated partially as in-patients and partially as out-patients, this form of new, flexible learning under the supervision and care of trained tutors is the key to success.

Since the start of 2002, young cancer patients of 12 years or older can take the European Computer Driver's License (ECDL) course at the oncological wards of our two main children hospitals in Vienna.

At the beginning, 16 hospital care workers (teachers, kindergarten teachers, employees of the Children's Cancer Aid Association) were trained as so-called disseminators. These individuals completed the ECDL course in June 2002.



We considered this training step to be an important factor to prevent hospital-internal contact anxiety. The competence gained in working with the media allows qualified and emotional support for the patients.

Afterwards, the training of youths and young adults began in May 2002. After fulfillment of various criteria (e.g. age, system requirements), the patients are accepted into the ECDL learning group.

We consciously refrained from including the medical prognoses in the selection criteria. Only the will and the desire of the patients count. Through the interactive networking and computer-aided learning programs and the methods of hybrid training, the youths can complete their training either at home or in the rooms of the Children's Cancer Aid Association or in the hospital, depending on their situation and treatment phases. The tests generally take place at e-train, the IT location of die Berater. The youths prize this "normality" far from the mental proximity of their illness.

The tests can also take place in the hospital in exceptional, health-related situations.

The training also influences the social network (siblings, parents, teachers, etc.) positively, such that this group is also distracted from the illness.

Currently there are 64 participants in this project, of which 13 youths have obtained the ECDL completion certificate, 11 died during the project and 7 left for motivation reasons.

### What exactly is the ECDL ?

The European Computer Driver's License (ECDL) is an internationally recognized and standardized certificate that confirms that a computer user possesses basic and practical computer skills. This certification covers the general use of the computer as well as the typical office applications and searching for information and documents in the Internet.

### What do I need the ECDL for ?

To be able to prove my computer skills on the job or during the job search. Anyone who has completed the ECDL is capable of using the computer as a tool in his or her daily work. The ECDL is the foundation for all computer users and represents a good starting position for more in-depth IT educations.

### How many modules are there?

The ECDL includes seven modules that can be completed in any order:

- Module 1: Basics of Information Technology
- Module 2: Computer Networking and File Management
- Module 3: Text Processing
- Module 4: Spreadsheets
- Module 5: Database
- Module 6: Presentation
- Module 7: Information and Communication

### How do I get into ECDL ?

Contact either the station psychologist, the Kindergarten teacher, the instructor team or the Children's Cancer Aid Association.

### Initial meeting with the trainer

- In possession of a computer that has Internet access, sound card and speakers
- At least 12 years old

### How do I study for the ECDL ?

At the start, every participant receives brief instruction in the optimal use of the software. During the self-study of the training contents, an attendance phase takes place during which open questions can be clarified or concrete examples can be worked through as exercises. The length of this phase depends on the module.

After positive completion of all seven subtests, one receives the European Computer Driver's License.

We have learned one thing from the positive experiences with this project so far: not only the desire to learn helps the youths forget a little of their suffering, it is also the communication with each other – the formation of peer groups (groups with common interests and goals) which results automatically from the shared meetings, the learning groups and via the internet. It makes a significant difference to the situation of the individual whether one only discusses the illness or also talks about a shared problem, such as in a database application with Access.

The enthusiasm with which the course contents are absorbed and the commitment given to the challenge of "computer work" are sensational.

### What the participants say about this project ...

I always looked forward to these shared hours because I met new friends there and we always had tons of fun. There was always a very casual mood for the tests. We always knew that we could do everything and were hardly nervous. I was a little nervous for module 1 (theory).

*Sebastian, 12 years*

It was very important for me to be distracted in this way during the chemotherapies.

What I particularly liked: that I did not have to study alone for the seven tests or modules, but that I could also study with the other patients who were participating in the project at the hospital and that we were also together in the course and at the tests.

*Natascha, 13 years*

It was totally great because I was given the opportunity to do something for my further education despite my illness.

*Stephan, 14 years*

*Erich Wurzinger, Stefan Kremser, Elfi Schattauer*

# How parents can help themselves and others in the family, in providing effective care for the sick child

The key to an effective, satisfying and holistic response to a situation lies in its clear, objective, and comprehensive understanding. As is said, "The best educated man is he who understands the circumstances he is in." The truth of the above words may be felt in our day-to-day lives. A crisis – as a serious illness of a loved one – only makes it more imperative to address the complexities of the time in a very correct and comprehensive manner. Such an appreciation of the realities calls for a very dispassionate and objective assessment of the situation at hand. This objectivity, however obvious, is not an easy sentiment to achieve. When such a situation involves somebody with whom we have associated the purest and most honest of our sentiments, this objectivity is even more elusive.

It is very difficult – if not incorrect – to be normative in assisting parents in such a circumstance. While dealing with the human mind, you cannot put things in black and white or make blanket generalizations. It is never advisable to advocate "One best way". Every individual is different from the other. In my capacity as a psychologist, I have focused on helping parents make the best use of the support system that is available to them. Such a system may comprise the family, relatives, friends, co-workers, other parents in a similar situation, the medical staff, and organizations like ours. I endeavor to present the parents with a choice of various support groups and assist them in making a choice that best addresses their unique needs.

This paper has been drafted in the same spirit. This is not intended to be a prescription for those in the unfortunate position of a parent of a child with cancer. If I may make the parents consciously aware – conscious being the key word – of the options available to them, and then select their sources of support, I would consider this essay a success.

The focus of this paper is or, "How parents can help themselves, and rest of the family, including the child to care more effectively". I propose to address the topic with a two-pronged approach.

Helping the parents get an insight into the psychological aspects of the situation.

Helping the parents identify and adopt the most potent support groups to create an effective support mechanism for themselves.

1. Helping the parents get an insight into the psychological aspects of the situation.

Problem solving is a complex process that has a variety of influencing factors. These include your feelings about the situation (personality characteristics), the relationship between family members, the flexibil-

ity and openness to a new approach, and the effects of other life events. Parents must also be helped with the realization that when they are dealing with a diagnosis of cancer, it may not be possible for them to control everything going on in their lives. Parents must be helped to overcome the hesitation – and also the fear of seeking support. It may take some time for them to determine how much of themselves to share with others. But as social beings, we must appreciate that some needs lend themselves to being better addressed in a support group – examples are needed for information, such as how children typically react to diagnosis, how to explain this diagnosis at your workplace, and how to communicate better with your doctor. Only when the parents feel less overwhelmed about the situation then they might be able to offer a more effective front to the crisis that life has posed for them.

Over the entire life cycle of the disease and the treatment cycle, parents vacillate between various intense sentiments. For instance:

- The initial diagnosis may create feelings of confusion, denial, hope, fear, anger, guilt, grief. The parents' belief in life and their faith are severely tested. These feelings need to be put to rest to the extent possible by effective counseling as they hinder parents' efforts to face the situation squarely.
- The breaking of the news of the diagnosis to the child, the family, and other elements of the parents' society (as friends, relatives etc.) instigates a lot of apprehensions, fear, and guilt in the parents. I came across a serious patient whose family requested me to park my van away from their home lest neighbors should know. Being secretive entails a lot of avoidable tension.
- Hospitalization of the child involves the parents in dealing with the feelings of trauma, anger, confusion, uncertainty, restriction, and depression in the child. The child may show extreme behavior as either withdrawal, or attention-seeking. Such situations are emotionally trying for parents and children. They must be handled as the situation dictates, but parents must be sensitive to their own child's need for understanding, reassurance, and reaffirmation of hope.
- Going home from hospital is another huge change in the lives of the child, the parents and the family as a whole. Establishing normality in the home is the basic task facing the parent. Parents must realize the importance of not being overprotective towards the sick child. This would only create dis-



pleasure and resentment in the other children at home and also prevent the child from feeling normal. An encounter with another child who has improved from similar situation is a source of strong motivation to the patient.

The parents must also address the concerns of schooling, teachers, peers, and the continuing medical treatment.

■ When the treatment ends, there is a complete change in the life of the parents. Coping with the shock of diagnosis, the pain and anxiety of treatment, and the disruption of daily life requires a boundless reservoir of courage and compassion. Now the focus must change again. For most families, the end of active treatment eventually leads to a cure. For some, sadly, it ends in death. But regardless of the outcome you must give yourself the credit of facing the struggle head on.

The post-treatment phase is generally characterized by a fear of recurrence, over protectiveness towards the child, developmental issues of the child, meeting sibling needs, putting the illness in place, re-establishing family life, and providing an emotional buffer for the family.

Meeting the demands of the diagnosis and treatment of cancer creates an enormous stress for the parents. Managing such contradicting sentiments, such uncertainty, and such trauma is not something for which we are geared up naturally. We must seek the help of people and organizations who are willing and able to help. Children are not meant to suffer such pain and agony. We must, therefore, pool all the available resources and support to provide an effective redressal for the concerns of the child. How ever strong a person might have been in dealing with the stresses of personal and professional lives, he would always find the diagnosis and treatment of cancer an excruciating task to handle. This is where organizations like ours step in.

2. Helping the parents identify and adopt the most potent support groups to create an effective support mechanism for themselves.

Once we have established the need for adopting a support mechanism, we must now proceed to present the various available options to the parents. These options must be evaluated and adopted according to their relevance to the situation and the comfort level of the parents. The parents have to reconcile their various roles as brothers, sisters, sons, daughters, professionals, parents to other children, friends and members of the society. Any let up on any of these fronts may create a feeling of inadequacy or failure in the parent and hinder the caring of the child. Our ultimate objective is to care effectively for the sick child. However, we must ensure that our actions are sustainable over a period of time and that they do not stress the other aspects of the lives of the parent. Stressed marriages, and behavioral problems in other children are amongst

the most common of fallouts of an impulsive handling of the situation. Therefore, all the stakeholders in our lives must be considered and addressed correctly and adequately to present a sustainable, just and enduring caring mechanism for the child.

If I were to derive the commonalities from the various interactions that I have had with these families, I would present the following aspects as the most important and perhaps critical elements for ensuing a healthy and effective caring of the sick child.

**Relationship between the parents:** This seems to be the strongest source of support. Parents who shared a healthy, trustful, and supportive relationship with their spouse have generally fared better in caring for the child. Such parents must appreciate the concern and involvement of the spouse. Communication between parents should be considerate, clear, concise, and trustful. It might happen that one of the parents (especially the mothers) become oblivious to the requirements and concern of the spouse. This is very natural. This is also very harmful for the ultimate objective of providing a good and fulfilling support for the child. Parents are the strongest pillars for the child. Therefore, they must ensure that their relationship is made stronger by this bond of endurance and does not wither away under the strain.

**Relationship with relatives, grandparents and friends.** Our social interactions are a source of great help in dealing with situations of such overwhelming magnitude. These associations help us vent our feelings and also make us feel secure. Such associations must be leveraged to gather the maximum support.

**Hospital staff:** The hospital staff, perhaps, is the most mature group in handling these situations. They have seen it all from very close quarters. They have experienced a lot of pain and hope with various patients and parents. They understand the most fearsome and intimate of their concerns. There are cases where parents have actually developed great regard and good relationship with the hospital staff. The unbiased opinions support, and information from the hospital staff has actually helped parents get an assurance that their child was getting good care. Interactions with doctors enables the parents to recognize the competence, efforts and integrity of the doctors, instead of blaming them and suffer from any sense of remorse and repentance if the child does not survive.

#### **The affected child:**

Surprising though it may sound, the sick child himself has often been a source of great inspiration and support for the parents. Very often, the courage, patience, and determination shown by the child in undergoing treatment helps the parents firm up against the odds of treating cancer. If your child is fighting it out with such grit and determination, do you have any other choice?

**Other parents.**

Parents of other children who are suffering from cancer also form a good source of support to each other. Empathy is a strong reliever and forms a strong common bonding between the parents. This association is a great outlet for any feelings of "victimization" and "why our child?" that the parents may be having. Its always easier for parents to accept the help and advice of another parent because it comes from a source that they can identify with and whose concerns are very similar to theirs.

**Religion.**

Religion has always occupied a high place in being a provider of succor for the emotional turmoil associated with the diagnosis and treatment of cancer. For the believers in the benevolence of the Almighty, it is a satisfying feeling to realize that their child is being looked over by God. Religion also helps parents to accept the situation with the serenity that flows from a strong faith.

In conclusion, I would reiterate that dealing with the diagnosis and treatment of cancer requires a lot of help, support, consideration, and direction from a variety of sources. Parents must acknowledge and appreciate the contribution that these various groups can make towards the effective care for their child. Organizations like ours seek to provide support to parents. However, it would be of great help to themselves if the parents are open and receptive the role of the various groups. Parents must consider it as their responsibility to develop and nurture a good support mechanism for themselves and their families.

What I realize from my dissociation with Sahayata, is that treating cancer has a lot to do with medical assistance. However, as a family, it has also got a lot to do with faith, hope, and patience. These values – faith, hope and patience – are therefore very essential to be upheld.

*Dr. (Mrs.) Nirmala Chaudhry  
Sahayata, Chandigarh*

**Announcement**

**Dear members, dear parents,**

For several years, ICCCPPO has been involved with SIOF in the writing of psychosocial guidelines to assist children with cancer and their families. The guideline theme for this year's SIOF meeting in Cairo was: "LISTENING TO THE (DYING) CHILD". Although ICCCPPO was not present at this meeting, input from ICCCPPO is most welcome.

This year the committee recommends a different approach from previous years. Rather than merely listening guidelines for listening to the child with cancer or leukemia, the meeting this year consisted of a discussion of examples of what it means to truly listen to a child, based on actual conversations and responses we ourselves had with the children. The goal was to start a process by which in the next couple of months the committee would collect stories and examples of truly listening to the child, organize the best of these into a unified form, and use the final product as a basis for discussion at the next SIOF meeting (in 2004 in Oslo, Norway).

To help the committee prepare a working draft for the 2004 Oslo meeting, we ask each ICCCPPO member to collect and send us by the first week of February examples of four or five actual conversations between a child and an adult in his/her environment (parent, physician, nurse, psychologist, social worker, other health care professional), followed by a judgment of the "listening" adequacy of the response, and a suggested alternative response. We are not limiting the

examples to children in the terminal phase, but wish to have examples from the treatment phase as well.

We would like each example to follow this format:

- a** the question (verbatim) that the child asks (or statement the child makes), and the circumstance in which the child asks/makes it;
- b** the response (verbatim) of the adult (parent, physician, nurse, social worker, psychologist, other health professional);
- c** a judgment of whether or not the adult's response was truly "listening" to the child; and
- d** a suggestion for what a more appropriate "listening" response might have been.

Clearly, parts **a**, **b** and **c** will be easier to do than part **d**. It's not easy to suggest an appropriate "listening" response. But it is part **d** that will give our guidelines their true value.

Please send the examples in the suggested format by e-mail to: **icccpo@vokk.nl**

We are looking forward to receiving your responses, so that we can prepare a proposal to the writing committee. The goal, ultimately, will be to publish the best examples, as we have done with our past "guidelines."

Thanks in advance.

Sincerely,

**Marianne Naafs-Wilstra,**  
*ICCCPO Executive Committee  
SIOF Working Committee on Psychosocial Issues*

Anne Grinyer

## CANCER IN YOUNG ADULTS: Through parents' eyes

Facing a diagnosis of cancer and possible death in their children is a nightmare for all parents. When the patient is aged between 18-25 –an age group when cancer is rare – the psycho-social problems that arise may differ from or assume a new importance from other age groups. But because there has been little research on the subject, the difficulties encountered by families are frequently not well understood.

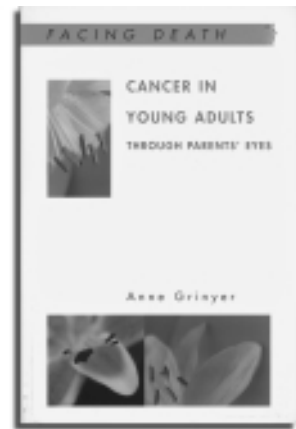
This book is designed to bridge the gap. Following an appeal in various newsletters, several parents submitted informal, written accounts of how they experienced their adult children's illness to the author. Even though the survey does not claim to be representative, the author has clearly identified topics such as loss of independency, questions of fertility and sexuality and ownership of medical knowledge as being of central importance to this age group. The impact of illness of a young adult on family life, siblings and marital relationships is also looked at closely.

Each topic-related chapter consists of three parts. The first tracks the different stages of one mother's experience whilst her son George was suffering from osteosarcoma. Part two expands her thoughts with extracts from the material submitted by other parents and the last section offers in summary a more theoretical viewpoint. The result is a digestible reference guide, leaving the reader free to skip or dip. The book is geared mainly towards the professional health carer, but its unique blend of personal narrative and theory also makes excellent reading for interested parents.

*Sue Grant*

OUP, Facing Death Series, UK Ed. David Clark, 2002, £19.99 (paperback), £60.00 (hardback)

ISBN: 0-335-21230-1 (pb) and 0-335-21231-X (hb)



Michelle Noyes and Helen Irving

## PALLIATIVE CARE FOR CHILDREN WITH CANCER A GUIDE FOR PARENTS

**Brisbane: Royal Children's Hospital, 2002**

A very helpful guide for parents and caretakers in support of the most difficult time in the life of a child with cancer.

Copies of this guide can be ordered from:  
Rebecca Rieson · Managerial Assistant  
Haematology, Oncology & Stem Cell Transplant Unit  
Royal Children's Hospital, Brisbane  
Herston Road, Herston · Queensland 4029 · AUSTRALIA

PH: 61 7 3636 1357, FAX: 61 7 3636 9051



## Beneath the Tree of Kindness: Me, my illness and the Family House



Family House, a non-profit organisation in Japan that provides accommodation at minimal cost for families caring for their chronically ill children, recently published the book *Beneath the Tree of Kindness: Me, my illness and the Family House*.

Family House was launched by the parents association of the pediatric ward of the National Cancer Center Hospital and members of the medical profession. It has been

operating houses where families with children of incurable diseases, such as pediatric cancer, who have come from distant locations can stay while they attend their children. It currently operates seven such facilities with a total of 37 rooms.

The book, was published in June. Some children who return to their schools and communities after having endured the ordeal of treatment discover with shock that their friends do not understand what they have come through. The book was produced in the hope of helping these children to be warmly welcomed back into society and of letting more people know about Family House.

Family House devised a unique system of distributing these books to schools across Japan. They call on people to "adopt" a copy of the book by donating in units of 2.000 yen, and for every 2.000 yen contribution, they send a copy to an elementary, middle or high school in Japan in the donor's name.

*M. Naafs*

Published by Family House  
4-19, 2-chome, Higashikanda, Chiyoda-ku  
tokyo, 1001-0031 Japan  
e-mail: jimukyoku@familyhouse.or.jp  
[www.familyhouse.or.jp](http://www.familyhouse.or.jp)

Books

## Executive Committee

**Simon Lala**, Chair

15 Jack Conway Lane (Box 76442)  
Manukau City, New Zealand  
Tel.: +64(9) 575-7785, Fax: +64 (9) 262-2132  
e-mail: [simon.lala@xtra.co.nz](mailto:simon.lala@xtra.co.nz)

**Geoff Thaxter**, Vice-chairman

1 Betjeman Close, Coulsdon  
Surrey, CR5 2LU, England  
Tel.: +44 1737 555411  
e-mail: [thaxter@ltrust.freemove.co.uk](mailto:thaxter@ltrust.freemove.co.uk)

**Christine Wandzura**, Secretary

609 14th Street, NW, Suite 205  
Calgary, Alberta T2N 2A1, Canada  
Tel. +1 (403) 216-9210, Fax +1 (403) 216-9215  
e-mail: [wandzura@kidsccc.org](mailto:wandzura@kidsccc.org)

**Julian Cutland**, Treasurer

50 Dawn Drive, Northcliff  
2195 Johannesburg, South Africa  
Tel.: +27 (11) 678-3803, Fax: +27 (11) 678-4863  
e-mail: [cutland@icon.co.za](mailto:cutland@icon.co.za)

**Irina Ban**

Palmoticeva 25a St.  
11000 Belgrade  
Serbia and Montenegro  
Tel.: +381 113246169, Fax: +381 113291219  
e-mail: [ban@yubc.net](mailto:ban@yubc.net) and [cepina@email.com](mailto:cepina@email.com)

**Mark Chesler**

Sociology Department, University of Michigan  
1225 South University (room 248)  
Ann Arbor, MI 48104-2590, U.S.A.  
Tel.: +1 (734) 647-3654, Fax: +1 (734) 763-6887  
e-mail: [mchesler@umich.edu](mailto:mchesler@umich.edu)

**Edith Grynszpancholz**

Mansilla 3125  
1425 Buenos Aires, Argentina  
Tel.: - Fax: 5411 4825 5333  
e-mail: [edith@fundacionflexer.org](mailto:edith@fundacionflexer.org)

**Marianne Naafs-Wilstra**

Schouwstede 2d  
3431 JB Nieuwegein, The Netherlands  
Tel.: +31 (30)2422944, Fax: +31 (30)2422945  
e-mail: [mc.naafs@vokk.nl](mailto:mc.naafs@vokk.nl)

**Ira Soelistyo**

c/o Rumah Sakit Kanker Dharmais,  
Jln. Letjen. S.Parmar kav. 84-86, Slipi,  
Jakarta 11420, Indonesia  
Tel.: 62-21-5681612 or 62-21-5681570 ext. 2030  
Fax: 62-21-5681612/7547745  
e-mail: [yoai2008@indosat.net.id](mailto:yoai2008@indosat.net.id)

**Secretariat:**

c/o VOKK, Schouwstede 2 d  
3431 JB Nieuwegein, The Netherlands  
Tel.: +31 (30) 2422944, Fax: +31 (30) 2422945  
e-mail: [icccpo@vokk.nl](mailto:icccpo@vokk.nl)



**Members of other ICCCPO committees:**

**Gerlind Bode** (newsletter)

Joachimstraße 20  
53113 Bonn, Germany  
Tel: + 49 (228) 9139430, Fax: +49 (228) 9139433  
e-mail: [Bode@kinderkrebsstiftung.de](mailto:Bode@kinderkrebsstiftung.de)

**Pia Bonini Serrafiero** (newsletter)

8° Strada 96, San Felice  
1 Segrate MI 20090, Italy  
Tel: +390 (2) 7533387, Fax: 390 (2) 7533387  
e-mail: [pia.bonini@tiscalinet.it](mailto:pia.bonini@tiscalinet.it)

**Sadie Cutland** (PODC)

50 Dawn Drive, Northcliff  
2195 Johannesburg, South Africa  
Tel.: +27 (11) 678-3803, Fax: +27 (11) 678-4863  
e-mail: [cutland@icon.co.za](mailto:cutland@icon.co.za)

**Mokhtar el Harras**

Association l'Avenir  
Route de Qued Akrach-Hay 11  
Angle Rue Bani Jadr et Bani  
Rabat, Morocco  
Tel.: - Fax: +212 (37) 713357  
e-mail: [mokhtar@iam.net.ma](mailto:mokhtar@iam.net.ma)