Notes by the editors

Incredible India! ... was the slogan for the 2007 SIOP conference site Mumbai (India). And as the annual ICCPO meeting was again held jointly with the SIOP-conference, the slogan was announcing the ICCPO annual meeting as well.

In fact, it was incredible: numerous parents from all over the world, including a large delegation of Indians, came to attend a week long conference – filled with lectures, workshops, meetings and – of course - fun!

The hosts, specifically Shubha Maudgal and others from the Cancer Patients AID Association have done their outmost to have it all beautifully organized. There were many possibilities to get in contact with each other, discuss and exchange views and experiences. The annual Assembly admitted 8 new groups to the membership and thus letting ICCPO grow to 105 members from 65 countries. The new board is presented in the following “Chairman’s Address.”

This newsletter issues reflects some of the issues presented and discussed at the conference. Unfortunately, we do not get all presentations delivered for publication, but we urge everybody to send us their articles to make the newsletter a lively picture of different areas of work within the ICCPO community.

This will also be the last issue organized and published by Gerlind Bode, as she is retiring from her position within the German Cancer Foundation. She still will be involved in the organization of the ICCPO/SIOP-conference in Berlin together with Anders Wollmén (Sweden) and Anita Kienesberger (Austria) who are responsible for the program.

Opening ceremonies of the SIOP conference in Mumbai 2007

Responsible for the next newsletters will be Sarah Talbot-William from CLIC Sargent (UK) and – we hope so – many volunteers. Some have promised to donate time to the newsletter while we discussed the issue in Mumbai, such as Surabhi Kakar (India) and Nazli Müdöroğlu (Turkey). And we hope that there are many organizations sending their contributions (from now on to: sarah.talbot-williams@clicsargent.org.uk).

We wish you a prosperous and healthy year 2008!

Gerlind Bode
Marianne Naafs

These wishes for the New Year were sent to us from Nepal:

HAPPY NEW YEAR 2008

I wish you Health...
So you may enjoy each day in comfort.

I wish you the Love of friends and family...
And Peace within your heart.

I wish you the Beauty of nature...
That you may enjoy the work of God.

I wish you Wisdom to choose priorities...
For those things that really matter in life.

I wish you Generosity so you may share...
All good things that come to you.

I wish you Happiness and Joy...
And Blessings for the New Year.

I wish you the best of everything...
That you, so I will deserve.

Shambu Prasad Kadariya
Cancer Society Nepal
www.cancersocietynepal.org.np
The Chairman’s Address

We start by thanking Simon Lala for his work as Chair over the past 4 years. Simon has been instrumental in a number of developments, including WCCF. Simon continues on the Board as Treasurer.

We also say thank to Chris Wandzura, Canada, who leaves the board after 12 years service. She has made an exceptional contribution over the life of the organisation and has agreed to remain as the continental representative for North America.

We say hello to Anders Wollmén, Sweden, who joins the board, having already been actively involved in the conference planning for Mumbai.

Also, we congratulate Benson Pau, China, on becoming Vice Chair. Julian Cutland moves from Treasurer to Secretary.

SIOP Board

We say a huge thank to Professor Tim Eden who completed his term of office as President of SIOP in November. Tim has been a great advocate of ICCCPO, instrumental in setting up the World Child Cancer Foundation, and a dear friend to our board. We also welcome Professor Maarten Egeler as the new President. We share similar goals and have already agreed areas for joint working, mentioned briefly below.

Mumbai Conference

Our thanks go Chris Wandzura and Anders Wollmén, and to the local organisers Shubha Maudgal and Bharat Agarwal for an excellent conference in Mumbai.

The organisation – past, present & future

ICCCPO has come a long way since 1994 - from 12 initial members then to 108 today. It continues to be an exciting time in the development of ICCCPO. Following a strategy review earlier this year, we have set a number of goals for the organisation. We aim to have a larger and stronger membership, which will enable more regional and continental work. And we aim to improve the way we facilitate the exchange of information and experience between members. Our work in Europe, Asia and Latin America is going well; and we continue to develop in other parts of the world. Our work in developing continental and regional structures will be a defining step for ICCCPO over the next few years.

We have the possibility through World Child Cancer Foundation over the next 2 or 3 years to provide real help in developing countries. We will work closely with SIOP, St Jude and others to ensure progress continues in improving survival rates and care standards in developed countries.

We continue to work closely with SIOP and have agreed some joint steps to support each other. These include developing membership, continental committee work, and increasing the voice of children with cancer to press for improvements in clinical trials.

Please remember this is your organisation! If you have ideas or questions, please get in touch.

With best wishes for 2008,

Geoff Thaxter

On behalf of the ICCCPO Board
Reports form the ICCCPO Conference in Mumbai 2007

My Child Matters

UICC and Sanofi Aventis jointly took up the program My Child Matters (MCM) to advance the fight against Childhood Cancer in countries where Paediatric Oncology is still struggling to emerge.

Palliative Care for children with cancer in Bangladesh

The ASHIC Palliative Care Unit (PCU) was started in 2006 sponsored by UICC and Sanofi-Aventis, under this MCM program. ASHIC takes the opportunity to offer its thanks to the UICC and Sanofi-Aventis steering committee for selecting this project.

Without the funding of EURO 60,000.00 from MCM, the ASHIC PCU project would have remained in cold storage for a longer period or possibly would never be implemented.

Before the start of the MCM program, ASHIC had no significant exposition to international funding and was inexperienced with regard to various problems, which were sometimes very frustrating. However, Geoff Thaxter (at that time Vice Chair of ICCCPO) was constantly guiding ASHIC through email and phone calls, on how to overcome the problems and manage the situations in difficult times. The ASHIC Foundation is extremely grateful to Geoff Thaxter for his support and encouragement, which has allowed ASHIC to bring the project to the present status.

How do we perceive Palliative Care?

Terminally ill patients who fail to respond to curative treatment go through a period of unrelenting pain and agony in their remaining days or months. Through pain and symptom management palliative care aims at making the last days of the patients as comfortable and painless as possible as well as providing moral and spiritual supports to their near ones.

It is needed by most children with cancer in Bangladesh

Of the estimated 6000 to 7000 cancer affected children per year in Bangladesh, a maximum of 10% gets hospital treatment. The survival rate of most of the patients who are treated in hospital, is very poor due to a host of factors like delayed diagnosis, financial difficulties, lack of front line professionals etc. There is no organized palliative care offered to the unfortunate children. As a result, there are many cancer affected children in terminal stages, those who pass their last days in extreme agony.

In the year 2000, we started a project, called “Shelter”. It is a 20 bed free accommodation near the Bangladesh Sheikh Mujib Medical University (BSMMU), the most recognized institution for paediatric oncology treatment in Bangladesh. So far, more than 170 children received the advantage of the “Shelter”. During their years long treatments these children had to come and stay in the Shelter many times. Thus we have specific data about them. According to our records only 19 children survived. Now, imagine their last days in a community where the family becomes isolated as their neighbors still believe that cancer is an infectious disease. With respect to this situation we felt that palliative care is a critical component for children with cancer in Bangladesh.

Setting up the Palliative Care Unit

The ASHIC Palliative Care Unit started in May 2006. It is a twelve bed all free facility (6 for patients and 6 for guardians), run by 4 doctors, 4 nurses, 4 social workers and 2 nurses aid plus a number of volunteers.

The facility is taking care of the terminally ill patients for a period of 5–10 days in first admission. During this period, while taking care of the child, parents are encouraged to participate with doctors and nurses in caring activities. Along with it, the social workers take the opportunity to counsel the parents on spiritual and other issues. This approach is taken in order to offer first hand training to parents on how to take care of the child while at home and to get them prepared for the worst. After such training, the patient and family are transported to their home.

Our social worker who accompanies the family organizes a local community gathering to inform them about the family and to motivate the community to support them in a situation where human support is more important then medical care.

After the children are settled at their homes, they are constantly monitored and supported by the PCU through phone calls and home visits.

Social workers are also regularly visiting the families in hospital for counseling the parents of the in-patient children in order to give an understanding of Palliative Care and role of the ASHIC PCU. So far, more than 2000 parents and relatives, in various hospitals were interacted in our counseling activity.

Training of doctors, nurses and social workers

A special group of the ASHIC Volunteer Corps (AVC) was organized in December 2006 to support the Foundation’s
activities. Among these volunteers are five oncology specialists, who received training in palliative care abroad. To our knowledge, there are only twelve such specialists available throughout the country at present.

Oncologists from the Volunteer Corps organized training programs for the doctors, nurses and social workers in order to increase awareness on palliative care. In the past 18 months we have already done six workshops, five seminars, seven training programs. More than 1500 people have attended.

The activities are already making a difference

Initially we had very poor response from families, doctors and hospitals. From the start in May 2006 to May 2007 we had only 35 patients admitted in the PCU despite all our efforts. Whereas the intake of patients in the PCU from June to October 2007 (that is the last four months) has dramatically increased. The total number of admitted patients (new and re-admissions) has crossed 144 to date.

- The training for the parents appears to be effective for home care as families and patients at home are found to be comparatively better settled and content. As well as the communities appears to be more sympathetic and supportive.
- Parents/relatives of the deceased children come to the PCU to express their gratitude and many of them tell us their tales of gruesome experience, of their unsuccessful, often year long treatment in hospitals and their financial trauma. Most of the families praised the role of the PCU and regretted not having had the benefits for their gone away children earlier.

Hospital authorities are realizing the need of Palliative Care

The authorities of Bangladesh Sheikh Mujib Medical University who found it difficult to accept the concept of palliative care and were not extending support to our program - despite our long standing support service from the Shelter to children under treatment in BSMMU - has opened a palliative care unit in the hospital under the leadership of Prof. Dr. Nizamuddin in October 2007. Dr. Nizamuddin in his opening speech frankly admitted that doctors in Bangladesh were not aware about the concept of palliative care until recently. We came to know that the National Institute of Cancer Research and Hospital is also opening a palliative care unit soon. We consider this to be a significant mile stone of our campaign.

Slowly people are showing interest to be a member of the AVC (ASHIC Volunteer Corps). A chapter of AVC in Sylhet, another district town 200 km from Dhaka, is in the process of formation. We are organizing a training program in Sylhet for 40 participants of doctors and nurses to be selected by AVC members of the Sylhet chapter. The training will be conducted jointly by the AVC oncologists and expatriates from the UK arranged by Geoff Thaxter from MCM funding.

The Dhaka Medical College, the number one medical college and hospital in the country is also now realizing the importance and appreciates the need for palliative care. So, we hope it is not far away that palliative care will be taken up as a national agenda for patients of all ages.

Lessons learnt

We believe palliative care is the most important item in countries where medical facilities are insufficient. But it is felt that this new concept has little acceptability as doctor’s preference is to focus on patients with hope of recovery more than on those who no longer respond to treatment even though the majority of children falls under this category.

ASHIC is working hard to make the project a success. However, the progress has not yet been at the anticipated place because of little acceptability of the palliative care concept both by doctors and the society. Therefore, sufficient social interest could not be generated for fund raising from local sources and we see a weakness in the project’s sustainability without assured funding from international sources for an extended period.

Transportation of terminally ill children by public transport to their home village is very difficult and risky. We will need ambulance cars and more ambulatory facilities for palliative patients.

We also need:
- Seminars and workshops
- media publicity
- outreach programs on home care and community support
- access to palliative medicines.

This can be done with
- Assured availability of funds and fund raising
- Government policy to provide better access to palliative medicines which are restricted to control drug abuse.
- More volunteer members in the AVC to support ASHIC activities nation wide
- Regional centers of service and develop community support
- More media awareness, advocacy and lobbying.

At this point, I would like to mention a few names, who have helped ASHIC to go ahead with the project: Prof. Dr. Tim Eden, Isabel Mortara and Jose Julio Divino of UICC, Caty Forget and Catherine Boniface of Sanofi-Aventis. ASHIC appreciates their involvement in the project, and would like to say Thank you.

Afzal H. Choudhury
ASHIC - Foundation for children cancer, Dhaka, India
www.ashic.org
My Child Matters

Early Detection Campaign of Childhood Leukemia and Retinoblastoma

INDONESIA An integrated community-based detection and treatment referral campaign for leukemia and retinoblastoma in childhood was supported by the UICC My Child Matters project in Indonesia.

In Indonesia, with a population of 220 millions, the incidence of childhood cancer is about 11,000 new patients per year. Leukemia and retinoblastoma are found to be the two major causes of mortality among children with cancer. As parents mostly consider the diagnosis of cancer a 'death sentence', they often refuse treatment or do not bring their children to the hospital at an early stage. Lack of information about childhood cancer in the general public also causes numerous problems.

Thus the Indonesian Childhood Cancer Foundation (YOAI – Yayasan Onkologi Anak Indonesia) as member of ICCCPO, designed with the grant of the UICC-project My Child Matters a program for early detection of childhood cancer and a system of treatment referral.

The project was created to achieve the following objectives:

1. Information on leukemia and retinoblastoma for parents and patients
2. Increased knowledge about theses diseases among health care providers
3. Improved community care and support for parents and their children with cancer.

It is done at 10 participating poor communities and 10 participating community health centers in Jakarta.

Our Aims
Within a five-year time frame, it is envisioned to have the following path:

Year 2:
More participating partners, mostly companies.
More participating areas in other poor community throughout Jakarta.
Piloting poor communities in other big cities in Indonesia (possibly in Medan, Surabaya, Bandung)

Year 3 and Year 4:
Striving to get a National Strategic Plan for the treatment of cancer in accordance with the model.

Year 5:
Striving to get the national budget for the treatment of cancer increased.

We are grateful to have been allocated this fund which has given us more awareness in the community and also made fund raising for our organization easier.

Lastri Krisnarto
Yayasan Onkologi Anak, Indonesia
lastri_krisnarto@yahoo.co.id
My Child Matters

Building a Future for the Children of Romania

ROMANIA P.A.V.E.L. stands for "Primind Ajutor, Viata Este Luminoasa" which means "Getting Help, Life Is Bright". PAVEL is a non-profit, non-governmental organization and was created in 1996 by a group of parents of children with cancer, leukemia and severe anemia in Romania. We are member of ICCCPQ, ECPC, EUROCHILD, FABC and soon, of UICC-PAVEL received a contribution from the My Child Matters – grant for optimizing the support of parents with children with cancer.

Project background
Weekly, about 120 children (age 1 to 19 years) are treated at the Fundeni Clinical Institute (Pediatrics wards I and II, hematology). About 50 children are treated weekly at the Oncologic Institute (Pediatrics department) of Bucharest and about 50 children weekly receive treatment at the Emergency Clinical Hospital M. S. Curie (Budimex), Bucharest.

- The children are coming from a large area of the country.
- There still is a lack of specialized services on cancer matter such as: social and psychological support.
- Good practices on cancer issues are missing.
- The communication and networking between patients and professionals as well as institutions is insufficient.

Main objectives of the project
- Diversification of the services and resources on the issue of children cancer for children, parents, professionals and NGOs by organizing and running a Resources and Service Centre.
- Increase of the awareness among parents, professionals and public in Romania about the prevention, treatment and services available in the field of childhood cancer.
- Reinforcement of the public/private institutional framework in order to promote the rights of children affected by cancer.

What we accomplished so far:
- Organizing and launching P.A.V.E.L. Resources and Services Centre in partnership with the Oncologic Institute from Bucharest;
- Work on the Centre's methodology and policy manual, such as personnel, reporting, evaluation tools, and clients files and intervention procedures was initiated;
- Conducting a survey in 2007 to identify the needs and expectations from various groups: children/youth, parents and professionals;
- Supporting 107 children/teenagers and their families by direct social and psychological services.
- Organizing a data-base and Cancer helpline (0800 800 421) launched on September 2007;
- On-going organization of a library for up-to date resource materials;
- Participation in meetings and workshops with decision makers, Romanian public officials, other NGOs for developing more awareness about the disease.

Contact: P.A.V.E.L. ASSOCIATION (ROMANIA)
E-mail: pavel_romania@yahoo.com
www.asociatiapavel.home.ro
LOBBYING: Talking with Government and other agencies

(Workshop conducted at Mubai meeting)

In July 2007 in New Zealand, one of two Paediatric Oncologists resigned her position at a child cancer treatment centre in part due to frustration that funding was insufficient to meet the need for a properly staffed and funded child cancer tertiary treatment centre. Given only one specialist remained at this particular treatment centre, and that one specialist was not capable of providing full 24/7 care, the tertiary treatment centre was closed to all new patients while a study and review of services was undertaken by a renowned specialist.

On 12 Sep 07, the specialist’s report was released. In relation to the issue of treatment, there were two possible options:

- Provide adequate funding for a full tertiary joint-service in conjunction with another specified treatment centre in NZ; or,
- Close the tertiary treatment centre and reduce the service to shared care status.

On 3 October 2007, the Hospital Board announced its decision:

"...to unanimously support working to restore a full tertiary service...."

The Chairman of the Child Cancer Foundation committee in that area exclaimed: “We did it.”

What happened that enabled the Foundation’s Chairman to be so ecstatic?

EFFECTIVE LOBBYING

A newspaper reports of what happened at the "emotionally charged" Board hearing:

“Several Board members were reduced to tears during presentations by cancer patients’ parents and doctors, who turned out in force”.

The Foundation’s staff member said “We must retain the essential service.”

A parent of a child with cancer said she wanted to speak out for other families “who don’t yet know their lives are about to being turned upside down.”

The Board decided in favour of the lobbyists.

What is ADVOCACY?

“The act of speaking or of disseminating information intended to influence individual behaviour or opinion, corporate conduct, or public policy and law.” (Sean Moore Pg 8)

Child Cancer – Our Motivator to Lobby

Cancer is suffered by children worldwide. Cancer does not discriminate – it occurs regardless of race, colour, creed, sex, wealth, geographic location, etc.

We don’t yet know why cancer occurs in children. However, clever people are devoting their talents to research in order to find the causes of cancer and the cures. The researchers have achieved some considerable success. Research has been responsible for the dramatic improvement in child cancer survival rates in the past 60 years.

In New Zealand in the 1940s and 50s, for example, less than 5% of children with cancer survived. The survival rate some 60 years later is now around 80%.

In New Zealand, as with other developed countries, 100% of the children with cancer will see a doctor and all will be treated. Of these, 80% will survive cancer. However, worldwide in total, it is assessed that only 20% of children with cancer will see a doctor.
In addition to lobbying in our own countries at a local level to improve the outcome for our own children, our lobbying should also be directed to redressing this dreadful shortfall for children in countries where there is no adequate treatment.

Many children who survive treatment for childhood cancer will live with the Late Effects of their cancer treatment for the rest of their lives. Late Effects may be wide ranging in nature and include the ability of the survivor to learn, see, hear, walk, run, have children, participate in the community,... and so the list goes on.

Research never stops in the quest for causes and cures of childhood cancers as well as to lessen the life long effects of Late Effects as we know them. In the meantime, children and their families suffer.

**Why Lobby? – Our Key Driver**

In asking what the purpose of our lobbying is, I would suggest that it is:
- To use the power of parents/caregivers to achieve the best possible outcome for children suffering from cancer.
- This is a matter very close to our hearts.

**Lobbying – Starting the Process**

To be effective in the treatment of childhood cancer, Health Professionals (HPs) and parents/caregivers need to work together in partnership. Combining the respective strengths of HPs and parents will provide the means to ensure the best possible outcome is achieved for children suffering from cancer.

In acknowledging the place of the HPs and the trust that is placed in them to treat and care for our children, we also need to acknowledge a limitation in their ability to lobby. First, HPs need all their energy to help our sick children. Secondly, HPs are employees and in most cases employees have limitations placed on their ability to lobby to advance a cause.

Employers of HPs are invariably the funders, or the managers of funds, of the cancer service being provided. Thus, in order to start the lobby trail, it is important to establish contact with those the HPs work for – that is, their employers – hospitals, health boards, government departments

Some of you may be aware of the saying “He who pays the piper calls the tune.” Without doubt we need to lobby those who control the purse strings.

In our experience, it is the parents who can become powerful lobbyists or advocates in support of HPs needs. HPs care for our children so long as they have the means.

We must always be looking to raise the profile for Paediatric Oncology. We lobby to seek recognition and funding for skilled and dedicated HP staff, better facilities, new equipment, improved cancer treatment drugs, on-site facilities for parents, and for many other valid needs.

Naturally we must do this while being mindful of competing and perhaps equally valid claims made by those lobbying in support of other children’s illnesses.

**First Steps**

We lobby because constant improvement is needed to improve the outcome for children with cancer, and for our children’s children.

The first step in building a strong lobbying plan is for parents and HPs to identify and clarify the need – is it money, equipment, people, research, facilities?. This will help provide focus to the lobbying activity.

**Here are some tips on effective lobbying:**

*Focus and narrow the purpose* – Before lobbying commences for any specific issue, there needs to be a clear purpose. It is better that there is a smaller gain for a narrow purpose than no gain because the aim was too wide or diverse.

*Personal or general benefit* – There must be clarity in the purpose – is the lobbying for a personal crusade or for the wider benefit of the children

*Realistic* – Is the desired outcome of lobbying realistic, tangible, balanced

*Fair in context* – Is lobbying fair and in context with other competing claims for recognition, funding or support

*Reasonable* – Is lobbying framed in context of what reasonable people would ask for

*Power of emotions* – Remember to appeal to inner emotions as decision makers have children and families, too

*Generate friends* – To ease a staff member’s load, find out who of the decision makers’ staff will process the lobbying request and what they need from you, and in what format. Go the extra mile for them, and they might for you.

*Use of contacts* – “Not what you know but who you know” – Parents/caregivers, families and friends have considerable influence in the community.

**Consider getting HELP**

There is no single solution to successful lobbying, but there are many avenues that will help gain a positive outcome. Two important points worth a mention:

*Bury egos* – consider seeking help and advice from others to enhance lobbying. A solo passion for the cause may not be sufficient to round-out the case and sway the argument

*Expert advice* – Consider seriously the place for expert advice such as retired MPs, pro bono Lawyers, retired or volunteer political staff, professional lobbyists, consultants, university specialist, philanthropists
Graduated steps to get to the decision makers

Local parents groups or like minded parents
Local charities
Local Hospital Management – the Hospital CEO etc
Local Hospital Governance – the Hospital Board
Local municipal/City Councillors or Mayor
Local regional/State staff and elected/appointed representatives
Local Member/Representative of Parliament/Congress/Senate
Central/Federal Government – staff of Ministry/Department of Health
Central/Federal Government – Minister/Congressman/Senator
Central/Federal – Prime Minister/President

Principles to prepare a strategy

Bureaucracy - Overcome personal blocks and barriers against bureaucracy – a positive approach is needed at the outset in order to work for positive outcomes
Research - Research the background to provide depth to the case – time spent in preparation is never wasted
Prior information - Build on the past – don’t start from scratch if there is earlier work already completed on this issue
Collaborate - Consider the value of collaboration or support from other NGOs, charities, donor foundations and corporations
Depth - Involve and include other interested like minded supportive parties in order to prepare a well rounded collaborative effort e.g. HPs, parents, officials, staff, advisors etc
Best practice information - Ascertaining national/international Best Practice standards – the web has limitless information and is free
Competition - Consider and compare existing and likely competition from others for local & central government funding
Context - Consider the proposition in the context of political, policy and transparency issues faced by those the lobbying is trying to influence – try to understand their position
Reasonable - Don’t seek the impossible - ask for an outcome that makes it easier for the decision maker to say yes
Precedent - Consider the precedent this will set for the decision maker in relation to other charities – “if you were in their shoes, how would you decide ?”
Follow the process - Find out how the decision making process functions, follow the process and don’t cut corners for fear of offending a potential in-house supporter

One step at a time - Work through the established system but don’t go ‘political’ too early – let the staff members do their work in reasonable time before calling on their boss
Avoid confrontation - Ensure lobbying is inspirational and aspirational rather than confrontational – propose realistic outcomes and solutions
Use the Press carefully - Consider the use of PR and the Press, but not before exercising ‘proper’ channels as reactionary decision makers on the back foot are less likely to decide favourably
Sincerity - Be flexible to change, open minded and responsive
Open to offers - Be prepared to consider counter-offers in order to gain a win-win outcome
Integrity - Exercise respect and tolerance, have patience
Perseverance - Don’t give up at the first or subsequent knockbacks

Jim Barclay
CEO Child Cancer Foundation
New Zealand

We would like to inform you again about the non profit drug supplier:

IDA Foundation

IDA Foundation is an independent not-for-profit organization, established in 1972 in Amsterdam by a group of pharmacists committed to contribute towards greater accessibility of healthcare supplies in developing countries.

IDA’s core objective has remained to provide high quality essential drugs and medical supplies at the lowest possible price to the not-for-profit healthcare sector in developing countries, in particular:

- Intergovernmental organisations
- National and International NGO’s and aid organisations
- National Governments
- Public Healthcare institutions

IDA Foundation is the world’s largest not-for-profit provider of pharmaceuticals and medical supplies, offering a wide range of quality assured products from stock.

More information
IDA Foundation
P.O. Box 37098
1030 AB Amsterdam
The Netherlands
www.idafoundation.org
The missing link

... in Parent Support Groups in pediatric oncology in developing countries – The role of the clinical nurse coordinator (CNC) and the Jordan experience

Background
- Diagnosis of cancer is one of the most difficult challenges that patients and their families face.
- It makes them feel uncertain about the future.
- Prolonged time of treatment makes coping with the disease an exhausting process.
- So, they seek available resources to help with coping.
- All these issues make it necessary for parents to look for support from other people.
- People with the same kind of experience.
- Looking for understanding and mutual support, a support group is one of the major tools that people use to cope with their illnesses.

What is a support group?
A group of people with common experiences and concerns who provide emotional and moral support for one another (Merriam-Webster’s Online Dictionary).

The Nurses’ role in support groups:
- Historically, nurses have played a vital role in the establishment of the first support groups for people with cancer and survivors due to mutual involvement and the sense of care.

Nurses’ roles in supportive care of patients:
- Empowering patients through education.
- Patient’s advocate.
- Stressing on supportive actions (creating a supportive environment, close follow up of patients’ academic efforts).
- Team work.
- Striving for better understanding of the psychosocial effects that cancer brings on children.
- Being always there.
- A major line of defense against any misconduct.
- Helping people to cope with their illness.

The first parent support Group in Jordan:
- The idea started by a single person who realized the importance of establishing a parent support group in Jordan.
The group sessions started on November 2005. It was basically intended for parents of children with CNS tumors, started by us calling possibly interested parents and advertising the group meetings during clinics.

**Baby steps:**
- Group started to meet once a month.
- Good number of attendants at the beginning.
- Decreased later.
- The problem of organization.
- Lack of compliance.
- Many social and financial issues.
- Faced a period of depression.

**Stabilization.**
- By June 2006: the team decided to begin a fresh start.
- A team member (CNC) was given time for organizing the support group meetings.
- Things started getting more organized.
- Still lack of attendants.

**CNC’s role in Support Group meetings:**
- Attending sessions regularly to encourage more attendance.
- Holding some small talks at meetings for health education.
- Inviting experts in many fields (special education, occupational therapy, child development, vision rehabilitation, etc).
- Distributing some health education materials
- Translating international publications (NBTF, ABTA) on coping with illnesses into Arabic.
- Contacting a support group in America for mentoring.

**Results:**
- More rapport and stability of the group’s meetings and settings.
- Less dependability on health care team to publicize meetings.
- Things were going fine!

**After the ICCPPO meeting in Bali (April 2007)**
- We realized that we are way behind!
- Many issues had appeared.
- Jordan is not a member of the ICCPPO!
- We don’t have an NGO status.
- Minimum involvement of parents.
- No funding for the group activities.

**Decision to take the group to another level:**
- We opened the group’s meetings to other parents.
- Presented the results and achievements of other support groups in Asia to parents.
- Showed great results.
- Parents started enrolling more actively in the support group meetings after seeing some of the other parents achievements.
- Increased number of active participants.
- More active involvement of expert volunteers.
- We started attending as facilitators.
- Official recognition of the Support group’s activities in the Center.
- More acceptance of the medical team for the Support group’s efforts.
- This lead to higher rates of enrollment.
- The group became an influential power to persuade the management and health care members of their needs.

**And what we achieved**
- Establishment of a telephone network (by parents) to inform all members of meetings and any new issues.
- Parents started organizing their own agendas and distributing materials by themselves.
- Parents started bringing speakers and experts from the local community to discuss their children’s issues.

**Support group satisfaction study:**
- We started a study on parents’ satisfaction of the groups meetings, made a pilot study.
- Initial data were collected.

**Preliminary Results:**
- Good satisfaction of the group’s achievements.
- Satisfied with the information and knowledge they got.
- Parents were unsatisfied with the power that the group gave them.
- Unsatisfied with the number and quality of the group’s activities.
What about ICCCPO?
- Jordan is still not a member of ICCCPO.
- No NGO status for the support group.

What are the obstacles?
- We are still a developing country.
- Bureaucracy.
- Very difficult to start an NGO.
- Financial issues.
- Lack of compliance.
- Lack of medical team involvement.
- Gender differences.

How did we solve the NGO problem?
We started to work jointly with the Jordan Society of Pediatric Oncology (JSPO).

JSPO is a professional society of pediatric oncology professionals in Jordan, who study and treat childhood cancer in Jordan and collaborate with other professionals who take care of children with cancer in Jordan and around the world.

What is still needed to be achieved?
- More activities for the support group.
- Less and less dependency on the nurses and other health care members to support the group’s meetings.
- More powerful actions on the ground.
- Establishment of a local ICCCPO branch in Jordan.
- Getting more funding to support group’s actions and events through JSPO

What’s next for SIOP- Asia, Oman?
- A local ICCCPO branch will (hopefully) be initiated.
- Parents will be attending, not the medical team.
- The study results will be published.

Conclusion
- The ideal support group should be lead by parents, but we believe that special considerations in different countries may necessitate leadership of health care professionals in early stages.
- Support groups may give hope and act as a source of information and support for cancer patients and their families.

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Group-Photo at Regional ICCCPO Meeting in Bali (April 2007)
Second parent group meeting in Saint Petersburg (2007 August, 17-19)

RUSSIA When we started to plan the program of the meeting we proceeded from the experiences of the annual ICCCPO Conferences. The best specialists of Saint Petersburg and other regions of Russia were invited to give talks. The first part of the program was devoted to general issues and included specialists’ papers.

We had invited a member of the Finish parent association “Sylva” to talk about their work, and we learned from our European colleagues how they developed their organization in the past 25 years.

The head of the pediatric oncology in Saint-Petersburg, Dr. Margarita Belogurova, stressed the importance of cooperation of medical staff with the parents. As both are struggling for the same aim they should be a team. Dr. Belogurova presented statistics on childhood cancer in Russia and specifically in Saint-Petersburg. She demonstrated the increase of the cure rate in childhood cancer due to advanced modern medicine. She also pointed out that parents have a significant impact on these..

Psychotherapist Igor Shats devoted his talk to the psychological facets of his work with families who have a child with children. He mentioned problems and difficulties those families encounter and showed the best ways to cope with them.

In a question-and-answer session parents could address their questions to the invited speakers and were able to discuss many of their crucial issues. Thus an interesting discussion was initiated and continued even during lunch time. Everybody was thrilled with this opportunity and wanted to listen to responses of the specialists.

After lunch the training part of the program began.

The first workshop dealt with the topic “How to establish/start a parent organization”.

Then we presented an issue of current importance for every member - beginners and experienced ones: “How to find funding for the organization’s activities and how to set up a good relationship with donors”. Svetlana Shut (fund “Viden”) shared her experience as a recipient of donations, and Utta Kirchen, member of charitable organization “Karitas”, spoke about the expectations of donors towards the applicants and their requests. The fundraising issue was of great interest to everybody as the problems of getting money for the organization’s activities and projects are equal to almost everybody.

The famous reporter Galina Artemenko covered the issue of well-organized PR-campaigns. She explained the expectations the news media apply to the ways of information content and presentation.

The third part of the conference consisted of several reports on different topics, such as innovative projects.

At the end of the conference Irina Ban and Anita Kienesberger as representatives of the International Confederation informed the audience about ICCCPO and the advantages of membership. They invited parents to involve in regional communication and network, to establish regional committees which will work closely with ICCCPO.

The participants of the meeting seemed to be very satisfied with the lectures and the information they had obtained for their everyday work and celebrated this event with a lively party in the evening. The Ukrainian delegation sang their national songs, everybody took pictures and all were eagerly happily involved in discussions and plans for future joint projects and team-work.

Katerina Kiseleva
Children and Parents Against Cancer (CAPAC)
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3. Regional Meeting
...of cancer parent organizations of countries in former Yugoslavia

The Third Regional meeting of Childhood Cancer Parent Organizations was held in Sarajevo (Bosnia and Herzegovina) on the 29th June 2007. With the participation of 32 representatives from five countries from ex-Yugoslav grounds: Macedonia, Federation of Bosnia and Herzegovina, Serbia, Croatia and Slovenia. Parent organization from Sarajevo “A heart for children with cancer in the Federation of Bosnia and Hezegovina” organized successfully the meeting following the initiative and generous support of ICCCPO.

The meeting went on in a working atmosphere, in exceptionally good mood and the participants shared valuable experience. Everybody got the chance to represent the activities of the respective associations, to outline latest achievements in the field and present the difficulties they are faced with in their activities. Physicians held exceptional lectures, intended to the attending parents. There were many representatives of governmental institutions pointing to a notable cooperation they will manage to establish with the parents of children with cancer in Bosnia.

On behalf of ICCCPO, Anita Kienesberger welcomed all participants and expressed her deepest feelings for our joint initiative and cooperation. On behalf of ICCCPO, the document designed in Erice/Italy in October 2006 “Cure and Care After Childhood Cancer”, was presented by myself. Both parents and physicians, expressed their great interest in the above mentioned document. During the presentation, I invited people to express their opinion and it was more like interactive session than just a presentation.

The topics of this meeting were:
- The lack of psychologists on the Hematooncology Wards - the things, already established as “a basic need”, are still considered being a luxury on our grounds. Psychologists, social workers, play-therapists, physiotherapists, defectologists and speech-therapists have no place within a medical team. Medical staff also faces great problems since they experience a “burn out” syndrome, resulting from the lack of expert psychological help and support.
- The lack of cooperation with schools - for a child’s re-established education, there is no cooperation with a school. Children and their parents are left alone to manage and overcome hard situation; educators also face the problems since they do not know how to treat a child with cancer that attends school lectures.
- The lack of information for parents and children - we have noticed the big progress, there is many new booklets about illness but not enough.
- Accomodation for parents „Parent house“ - only a few local parent organization provided accomodation for parents and children.
Cancer children in Bosnia are alone – there is no place for parents to stay with their sick children on the ward and they can stay with them only 3 hours per day!

Childhood cancer is a taboo – a great number of ex-patients do not know the full truth about the nature of their disease; parents lie either out of fear or lack of knowledge.

Survivors – only Croatia and Slovenia have established active (more-less) Survivors group.

Partnership with medical staffs – almost all participants expressed their difficulties in communicating with physicians but also we have realized the great progress on this topic. Bosnian doctors have written a very nice book for parents about leukemia and they are on their way to have much better communication than before. Medical staff modified their attitudes towards the patients and their families; young patients and their families are less ashamed of their disease.

Public awareness – thanks to the activities of the Parents’ Associations, the public awareness level has been substantially raised in the course of the previous 3-year period: frequent public appearances, marking ICCD, collection and publication of brochures within the range of ICCCPO issues, inclusion of the physicians into the promotion of the said, foundation of Regional associations etc.

Fundraising – is still very difficult because most of our organizations are volunteer based and we all need professional help.

Office – except for the organization from Sarajevo/Bosnia and “Sanus” from Split/Croatia, all other organizations are working without an office and paid staff. It means that our work is from home which is very difficult because we all know that such kind of work is a full time job.

This is just a part of the problems we face every day. We have realized that just a few participants understand the meaning of being ICCCPO member and this is something we have to work on in the future. Available Information on the ICCCPO website is not enough because may people do not use the internet, despite the fact that they have access. For a better mutual understanding, we are going to prepare a questionnaire “What do you know about ICCCPO” so that we might have more details about parents’ expectations and some other issues.

Regarding further regional cooperation, we have organized a Regional Committee with five parents, representatives of their organizations or countries. These parents will be responsible for further regional communication and communication with ICCCPO as well.

We have decided to organize regional meetings every second year and the parents are welcome to attend any SIOP and ICCCPO meeting but could ask for the ICCCPO scholarship only in the year when there is no regional meeting. The 4th Regional Meeting will be in Skopje/Macedonia in June 2009.

Irina Ban
Belgrade (Serbia)

Last Newsletter with Gerlind Bode

This is the last ICCCPO Newsletter that has been compiled and edited by Gerlind Bode.

A Newsletter is the first thing a network like ICCCPO should have. It means communication with and between members, it means sharing information and experiences, and it means that all member organisations can feel that they are not alone. Gerlind knew that like no one else. Therefore she started in 1992, after the first international parent group meeting in Hannover, a newsletter which later became the ICCCPO Newsletter as you all know it today. At least 36 Newsletter came from her desk in Bonn, and (articles from) these are still available through our website www.icccpo.org.

On behalf of the editors – and I am sure I also speak for the ICCCPO board and all ICCCPO members – I want to thank Gerlind for her enormous contribution to our ICCCPO Newsletter. Thank you, Gerlind!!!

Marianne Naafs-Wilstra
1000 Computers for 1000 children with leukemia

TURKEY The campaign, “1000 new computers for 1000 children with leukemia” was started by numerous letters sent to LÖSEV saying, “If only I had a computer...” Till today, we gave 1000 brand new computers with the newest technology to children in hospital.

First a phone call came to the homes of our children by their brother and sisters working in LÖSEV’s Social Services Department saying, “I heard that you don’t have a computer and want one very much. Would you like to be our guest in Ankara (or Istanbul) and receive a brand new computer?” And before an answer, screams of joy are heard from the other end of the line. As a matter of fact, there can’t be a more significant answer than this. Some of them have to travel very long distances to receive the computer which they’ve been dreaming of. But they don’t feel tired at all, because in the end they are going to receive what they’ve been wanting so much. They are trained for two days by voluntary teachers. When it’s time to go back home they leave after kissing and hugging their teachers.

A nation can become an economic power with its young and dynamic population only if it transforms into an information society by educating its people. With this aim, we as LOSEV, have been implementing many projects on IT technologies for school age children who have ongoing treatment and for those who completed their treatment, in order to increase their level of overall performance and information.

As soon as our children are diagnosed, they are given an e-mail address at the hospital. Thus, while receiving treatment, they can chat with their friends, surf the web and forget their illness. When they get back home, they have the opportunity to communicate with their doctors, nurses and psychologists and receive immediate responses to their questions.

- We socialize these children who are deprived of many opportunities of social life during their treatment and try to eliminate their feeling of isolation.
- With special education methods, we aim to raise children who are self-confident, aware of their talent, creative, who plan to access the right information and unite their own values with global ones.

Some words from our children show their appreciation:

“I'm very happy to have a brand new computer. It’s because, my home and my hospital are far away from each other. So, now I have the chance to ask all my questions to my doctor via the Internet.”

Emre, 13 years

“I will be able to chat with my friends, thanks to my computer.”

Gizem, 10 years

“My computer arrived just in time to help compensate for my missing school terms during the treatment and also to set the basis for my future education. Thank you LOSEV...”

Hakan, 14 years

P.S: You may contact Turkish leukemic children and young adults via hastane@losev.org.tr

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How to establish a mentoring program in your home country

What is Mentoring?
The term „Mentor“ comes from the Greek mythology. According to Homer Odysseus told his friend Mentor to please look after his son Telemachos as long as he (Odysseus) was at war. And he said: “Please treat my son like a father and friend, accompany him, educate him and introduce him into the society.”

Today, Mentoring means a strategy to support young leaders in companies. The person with less experience gets supported and strengthened in his/her individual development and gains from the mentorship.

We use the term "Mentoring" when we talk about hospital visits of (long term) cancer survivors / young adults (= Mentors) to newly diagnosed children, teenagers or young adults = Patients).

Possible tasks for Mentors:
- To pass experiences to patients which only survivors can pass (personal exchange of experiences)
- To give informationen (e.g. about regional survivor groups, national survivor meetings, literature, homepages, ...)
- To give hope!
- To offer support to the patient (e.g. to be with him/her during a session with the doctor, ...)


Who?
It is possible, that mentorship looks very different, depending on who is the mentor and who is the patient!

General Requirements for Mentors:
- At least 18 years old
- At least 2 years in remission (after treatment)
- The mentor is convinced that he/she is able to do it
- The mentor attends the mentoring program regularly

What?
Possible tasks for mentors:
- (Regular) visits to the hospital and maybe also at home
- To take up contact with the national childhood cancer organisation, with the local parents organisation as well as with the hospital in your city
- Build up a group of other mentors (local/ national) and share your experiences with them
- Educate yourself in communication skills
- Define guidelines for mentors and maybe much more

When?
When can you do mentoring?
- You can start as soon as you want

Please be sure you are ready for doing this!
- It would be the best to first establish a mentoring program in your home country and to talk about others who want to be a mentor, share your ideas and prepare yourself for the visits.
- How often you do the visits depends on yourself!

Where?
Where are mentoring programs already established?
- Finland since 2000
- England since?
- Austria since 2005
- Germany since 2006
- Netherlands since 2006
- Other countries???

Guidelines for mentors
- To talk to somebody about his/her problems doesn’t mean that you have to solve these problems!
- Do “active listening” (listen not only what the patient says, but also the way he/she is saying something to you)
- Do not talk (too much) about your own experiences, but when you do, always remember everyone has different experiences
- Don’t be shy! (the patient might be more nervous than you and you are the mentor!)
- At the end of the visit: ask how it was for the patient, whether you should come again, what you can do better the next time, what was helpful, ...
- Maybe a few days after the visit: call the patient and just ask: “How are you?”
- Always remember: mentoring means to give something to somebody! You as a mentor give the patient the possibility to talk to you about his/her feelings, experiences, concerns,
- DO NOT GIVE MEDICAL ADVICE/ NO MEDICAL INFORMATION!!!

If you are planning a workshop, start with role playing:
- Sit. 1: You are a young adult, child is 6 years old. The child gets surgery in a week, one leg has to be removed. You lost one leg five years ago. Talk with the child about your experiences in a child sensible way. The parents are also in the room.
- Sit. 2: You are a young adult, the patient is 13 years old. He/she wants to talk with you alone, but mother/father is still in the room and doesn’t want to leave the room. Find words to get a good situation to talk with the teenager.
International Childhood Cancer Survivor Network

Contact Report – December 2007

The 2007 survivor network sessions in Mumbai, India saw 38 participants from 13 different countries (Austria, Finland, New Zealand, Serbia, Canada, Germany, The Netherlands, Indonesia, India, Hong Kong, Japan, Philippines, Pakistan) come together. The age of the childhood cancer survivors who attended ranged from 18-49 years old with approximately 2/3 of attendees being female and 1/3 male.

This year, the conference saw our very first joint session with the SIOP nurses group, sharing information of interest to both groups, such as camps, development, mentoring. This session was a great step in the information sharing between different groups who play a part in childhood cancer and its survivorship. We enjoyed many great sessions, from both the survivor programme and joint sessions with both the ICCPO and different SIOP groups. I would like to extend my thanks to all who contributed to the survivor programme for Mumbai, 2007.

In 2008 we will again be arranging a survivor programme with the ICCPO conference, the conference will be held in Berlin, Germany. I invite any survivor or survivor group who is interested in helping out with the arrangements for the 2008 program to contact me so we can find a suitable area for you to assist with. Just to reiterate, the survivor programme is intended for childhood cancer survivors aged 18 years or over who currently play a role in survivorship activities in their own country, or who would like to establish such activities. If we don’t have contact with a survivor group in your country, or you would like to start a survivor group, please contact me and we can share some information.

I look forward to seeing many survivors at the 2008 conference in Berlin, Germany!

Prudence Walker-Cuttance, Chairperson
International Childhood Cancer Survivor Network
iccsnetwork@gmail.com

One of the delegates of the survivors group wrote us a poem for this newsletter issue:

Agony
The truth of life
is beyond the irony
of all conceptions
and reverse of what I wished had happened

Gagan Ishwar Singh (Keith)
gagskeith@yahoo.com

Steps for establishing a mentoring program

1. Share your idea, find others
2. Make meetings with other mentors (to further educate yourself, to exchange experiences, ...)
3. Financing your group, get professional support
4. Make inform the hospital and the parent group
5. Make inform children, teenagers, young adults under treatment

If you have any questions please do not hesitate to ask us:
Eva-Maria Casata (Austria): survivors@gmx.at
Dorothee Schmid (Germany): dorotheeschmid@web.de
Survivors' Issues

Images of people participating in cultural activities.
Miraculous Lady RITA SHAH – a true story –

Astonishing but still the true - people in today’s world are so busy with their day-to-day activities that they have forgotten to concentrate on the minute things and importance of their lives. We hardly believe in miracles and ignore them but still there are some unsolved facts, still there are some people who have defeated death and Rita is one of them.

The Woman who has not only defeated death, but also is leading a healthy and comfortable life has set an example for all of us, despite the fact that her twin sibling died in infancy, her sister was suffering from depression, her father got her a step mom who left the house in unusual circumstances so you can understand that there was no love and affection for our dear Rita. As you know that it is difficult to sail a ship in the desert, she managed to sail the ship in the “desert of CANCER.”

Rita, who lost her mother at the age of thirteen, where kids are busy with the new things to come up in the life, got trapped with the diagnosis of cancer. Her late mother did not accept the diagnosis as she wanted her daughter to get married in the well settled family like other girls were getting married after a certain age. But unfortunately, God’s will was different. Rita was a brilliant student and hoped to become a doctor. She was still a student when her cancer started.

Fathers love to take their kids to roam around in a zoo, a park, or go to the movies. But Rita’s father took her to Tata Memorial Hospital for checkups. She once asked her father why she had to go to the Tata Memorial Hospital when she was not suffering from any diseases. Her father had no answer for his innocent daughter, he couldn’t even lie. She felt that her life was ruthless and she was a total trash for her father, knowing that she couldn’t even lie. She felt that her life was ruthless and she was a total trash for her father, knowing that she won’t bloom like other flowers. But soon she diverted her mind, her thought to religious & spiritual things. Such belief forced her to lead a new life, or you can say: Rita got a reincarnation.

Beyond spiritual and religious support, medical science has also played a vital role in her treatment. A large team of doctors participated in her treatment. According to Rita, these doctors are Gods for her. Rita was once asked whether the battle which she won against cancer was a miracle, self determination or a scientific victory.

In 1972, a tumor in the throat was observed by her family-GP, who gave treatment to cure the tumor. But when the tumor was not cured, the doctor performed an operation and sent tumor tissue to the J.J. Hospital for further diagnosis. At the hospital, the doctors suspected that the tumor was not benign and they sent a sample to the Tata Memorial Hospital, where it was confirmed that the tumor was cancerous.

Rita suffered from blood cancer. Her father was shocked to hear that. She got radiation therapy for one month in Tata Memorial Hospital and after two years (that was in 1974) she had to undergo a chemotherapy for Hodgkin’s Disease.

In the year 2002 it was detected that she was suffering from pericardia effusion and she got a heart surgery in Lilavati Hospital.

On 14th February 2003 her uterus had to be removed as it was found cancerous and she was treated with radio therapy, which cured her from the uterus cancer.

Rita and cancer were like companions staying together for 35 years fighting against it confidently and fearlessly. It was quite an impossible task to treat this disease and for Rita it was the dangerous one as it was difficult for her and her family to afford such high expenditure. Many hardships connected with the disease and the treatment did not discourage her to try to lead a life as normal as possible, even though her family suffered from a financial crisis.

She also had to look after her father and mentally ill sister. In order handle the family situation, she started a job hunt and got help by an Estate and Finance Agency to set up a beauty parlour in Mumbai. She can be proud about her achievements:

- Maharashtra Governor Award Winner on 19th March 1990.
- Indian Cancer Society honored Rita by interviewing her for the Video namely “You are the Cure” in which Bollywood superstar Mr. Amitabh Bachan had also given his views and which was displayed world wide.
- The beauty show which was organized by ZALWADI MITRA MANDAL handled queries regarding Skin, Beauty and Hair Problems.
- “V Care” has also honored Rita by presenting her the award of the first cancer survivor. It was handed to her by Mr. and Mrs. Gandhi.

She still has many queries not answered:

- Who is responsible for her total expenditure and precious time which she lost during the most dangerous cancerous diseases?
- Who will come forward and raise their hand to help Rita?
- What will Rita do if society, relatives, organizations, institutions wont step ahead to rescue her from the devastating situations?
- How will a cancer survivor lead his/her life after defeating the ferocious disease?
- Why does nobody help such people who want to lead a normal life?
Her Views:
- She does not want others having to experience the same conditions she suffered from.
- She feels that life has a lot of pros & cons and many different and unusual situations can be handled. But being a cancer patient she got strong will power, self confidence and mental strength.

Her Wishes:
- She desires to travel across the globe and also urges to visit holy Jain temples.
- She hopes that the family stays together.

Her Message:
“LEAD A FEARLESS LIFE AND WITH STAND AGAINST ANY DISASTROUS SITUATION WHICH DESTINY PLACES AGAINST YOU”

Rita Sha, Mumbai
ritaloveparas3@rediffmail.com

Age of Hope – a story –

Before my time, no one lived past 25 years of age. The radioactive cloud that surrounded the planet like the atmosphere, caused cancer from the moment a baby emerged from its mother’s womb and breathed air for the first time.

This atmosphere of death, they said, was caused by the last world war. Some called it the last of humanity’s foolishness and ignorance. Others called it God’s punishment -- or doomsday at a slow pace.

People married at the age of 14 or 15, or as soon as girls got their first period. Love was the very least reason for marriage, as survival of humanity took first priority. They also didn’t waste their lives thinking about the future, or ambitions, religion, pride, ego or dreams. So there was no more war, hunger or injustice anywhere in the world.

Every single day that blessed these people was the one thing they treasured. And this had been going on for 300 years. Until Terry was born.

Many said he was a miracle. He was the second coming, a messiah that would lead humans to salvation. Others said he was just another step in human evolution.

Terry was born without cancer
All the scientists in the world could not understand this extremely rare phenomenon. Even after many extensive tests, they could not find anything that made Terry immune to the cancer. He was healthy, bright and sensitive.

Terry’s parents died when he was eight years old, which was very common. Being told that he was going to live longer than anyone else in the world did not make it easier for the poor, grieving child.

“Until when?” Asked Terry.
“A hundred years, maybe,” answered his 17-year-old uncle. “If you live a healthy life.”
“But then what do I do?”

“Do what you do. Live. For the rest of us,” was his reply.

An innocent child, Terry did not really grasp the meaning of his uncle’s words. He was just happy that his uncle, his most favorite person in the world now that his papa and mama had passed, was still alive.

They were never apart. Wherever and whenever the uncle went, Terry tagged along. Terry never wanted another companion or friend. His uncle was his only friend and that was that.

Ultimately, this really concerned the uncle. His time was almost up. His condition was getting worse every week.

When he was gone, who would take care of Terry? Who would be the best single companion Terry would have?

But one day, Terry came to him: “Uncle, I think I’m in love.”

“Oh yeah? Are you sure?”

“Yeah, she is great. Funny, smart…”

Best wishes for you, kid. Keep on living no matter what. You have the greatest gift in the world. Don’t waste it. Live it. If not for yourself, then for somebody else. So long. Your uncle.

When Terry read the note Uncle had left for him to read after his death, he finally realized something, something that terrified him for the rest of his life: He would always be alone, no matter what.

And his fear proved to be true.

His wife died after giving birth to their first son. Terry was 25 years old when this happened.

At the same time, he became the oldest person in the world. Everybody in the world celebrated his birthday. This should have been the happiest time for Terry.

But Terry was far from happy.

He had lost his parents, his uncle and his loving wife. And since the son did not share his dad’s gift, Terry would soon lose his only son too.

He started to hate his gift. He wanted to be normal.

“But you are normal…,” said one of his friends.
"No! I mean normal like everybody else in the world!"
"We are not normal, we are dying of cancer."
"Dying of cancer is normal in this world. You all live and die happily. But for me, I just live and live and I'm sick of it already!" said Terry.
But he lived on, no matter that he liked it or not.
Soon, Terry was not only the oldest person, but he was also the angriest and bitterest person in the world. He was angry and bitter to every single person he knew, including his son, who gradually began to hate Terry.
When the son turned 15, he decided to live far away from his father.
Terry did not care. It was not that he did not love his son. He just thought it would be too painful to bury his only flesh and blood.
His friends were also starting to pull away from him. Terry did not mind either.
He was a freak now. Who wanted to be friends with a freak?
Soon after, he became the loneliest person in the world, living all by himself in a secluded house. He never came out and nobody ever visited his house.
Only some delivery men occasionally dropped by with Terry's daily needs.
And as the years went by, his existence became legend, a myth about the oldest person in the world. They said he was a white-haired, wrinkled man who ate children if they were naughty or misbehaved.
No one really knew anything about the real Terry since everyone who had known him little or well had died.
Until one day, a teenage girl holding a baby came to his door.
The girl did not have any hair left and looked very pale.
"Who are you?" asked Terry, who was then 50 years old.
"I'm your granddaughter," answered the girl. Then she showed him the baby. "And this is your great-grandson."
The girl had one of the worst types of cancer. Her hair was just the beginning. The cancer cells would attack all her internal organs one by one. Soon, she would not be able to see or eat or breathe. And since she had only a few weeks left of life, she wanted Terry to take care of her only child.
"Out of the question!" roared Terry in horror.
The girl looked at her grandpa with great sadness -- but she did not look surprised.
"You are afraid, aren't you? Of losing your loved ones. That's why you're keeping yourself away from all of us. So you won't get hurt when we die. It's all about you, isn't it? You and your gift," she said.
"It's not a gift. It's a damn curse!" said Terry bitterly.
"Is it a curse to have no horrible disease raging through your body? To live much longer than everybody else in the world? To be free of pills or capsules at every single meal? To be able to see your children grow up and marry somebody? To have grandchildren and great-grandchildren?"
"What's it for, if I also have to watch them die?" he said, softly.
"Have you ever considered that maybe it's not for you? That it's for them? So that you can tell them about life before their time? So that you can take care of their children when they're dying. So that they will always have you around, no matter what," his granddaughter said.
If not for yourself, then for somebody else... Do what you do. Live. For the rest of us...
His granddaughter's words hit Terry like a huge hammer on the head. He suddenly fell and cried on his granddaughter's knees and begged for forgiveness.
He realized how foolish and selfish he had been all this time. His uncle had tried to tell him so long ago, but he could not hear it. Or at least, he could not understand it.
And the one who finally made him understand was his grandchild, one he had only just met -- and would lose all too soon.
Terry took care of his great-grandson with great love and passion after his granddaughter died. He decided to open himself to everybody again and do exactly what he was meant to do in this world.
No one could forget the first time they saw a white-haired and wrinkled man finally come out of hiding and walk around in public. No one had ever seen a 50-year-old man before.
Just the sight of him made everyone's heart glow with hopes, dreams and a realization that Terry would always be around for all their lives.
When I was born, Terry was 102 years old.
He was happy and glad, knowing there was someone else to take his place.

Jakarta, Aug. 22, 2006
Priesnanda Dwisatria
Movie (DVD): Chasing Rainbows
Young adults living with cancer
Is a documentary that portrays six young people who are “living life while fighting for it”. They candidly are talking about fear, anger, finances, sex, infertility, family relationships, death, faith, future ...

The movie is not only very interesting to other young “survivors” but also to the care givers, the medical staff and friends and family.

More information and how it can be obtained on www.chasingrainbowsproduction.com

New Resources from CCLG

2007 has been a very busy year for the CCLG Publications Committee. At the time of writing, in early November, the Committee has produced 7 new leaflets and booklets with a further 4 due in print before the end of the year – see the list below. Those of you who attended the ICCCPO/SIOP conference in Mumbai this year are likely to have picked up copies already but if you require further copies do contact CCLG. Resources are free but you may need to pay for postage costs if ordering several copies.

New in 2007:
Bereavement: where to go for help
An 8 page guide for families and professionals when a child or young person has died from cancer.
Childhood Cancer – A fact sheet for GPs
This fact sheet is aimed at UK General Practitioners providing an overview of childhood cancer including background, problems during treatment, late effects and palliative care.

Children with cancer and pets
An 8 page leaflet for parents and carers of children with cancer who own pets. Provides simple guidelines on reducing the risk of catching an infection from a pet.
End of Treatment, what happens next?
A 32 page booklet for parents and carers of children with cancer. Aims to help answer some of the many questions and concerns that arise when the child finishes treatment for cancer.

End of Treatment...what happens next?
A 28 page booklet aimed at 10-16 year olds. Aims to help answer the many questions and concerns that arise when young people finish their treatment for cancer.

Due in print by end 2007:
Ben’s Bone marrow Transplant
A guide for young people undergoing bone marrow transplantation.

Choices
A booklet with suggestions for parents and carers when curative treatment for their child is no longer an option.

Facing the Death of your child
A guide for families covering all aspects of bereavement.

Parents Guide to Brain and Spinal Tumours
A guide for parents covering all aspects of care following diagnosis of a brain or spinal tumour.

The following leaflets and booklets are also available from CCLG and most are downloadable from www.childcancer.org.uk:
- Ben’s Bone Marrow Transplant (for young children)
- Biological Studies and Tumour Banking
- Brothers & Sisters – A guide for parents of children and young people with cancer
- Contact – A helping hand for families of children & young people with cancer (quarterly magazine)
- Grandparents: A guide for grandparents of children and young people with Cancer
- How to help Brothers & Sisters
- My Brother has Cancer
- Quest for Cure
- Reflections on Childhood Cancer: A book of Poems
- What’s the point of coming to clinic?
- When your Brother or Sister gets Cancer

Contact: CCLG, 3rd Floor Hearts of Oak House, 9 Princess Road West, Leicester LE1 6TH, UK. Tel: +44 116 2494460 Fax: +44 116 2549504 Email: info@cclg.org.uk
www.cclg.org.uk and www.childcancer.org.uk
Berta Jereb
The Little Knights
This booklet is – as Dr. D’Angio says in his foreword – “a memoir and a set of reflections written by a pioneering explorer into the wilderness of childhood cancer. It is a very personal recounting of the professional life and times of Professor Berta Jereb of Slovenia. She was among the first to devote her career to pediatric oncology, particularly in the systematic use of combined chemo-radiotherapy in the battle against the malignant disease of childhood.
Professor Betra Jereb is a retired radiology-oncologist of the University Ljubljana and a radiology-oncology docent at the Karolinska Institute, Stockholm. Her booklet was distributed at the SIOP conference in Mumbai.
For information contact:
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Zaloška 2, 1000 Ljubljana, Slovenia
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Anne Grinyer:
Young People Living with Cancer
ISBN13: 9780335221547
ISBN10: 0335221548
“This is an absolute must to read for all those who care for young people with cancer, including the patients themselves, parents, doctors, nurses, psychologists and all of the caring professions.”
Professor Tim Eden, Christie NHS Trust, Manchester, UK

Also by Anne Grinyer:
Cancer in Young Adults: Through Parents’ Eyes
ISBN10: 0335212301
Practical advice on a number of issues including sexuality and fertility, finances and the emotional consequences of illness (Amazon).

Note: The picture booklet
Radio Robby
has been translated into Italian and can be obtained from:
Dr. Heike Möhlen
Medico Reparto Padiatria
Ospedale Regionale di Locarno
La Carità
Via dell’Ospedale
6601 Locarno, Switzerland

A very helpful practical guide for parents and patients has been published by CHOC (Childhood Cancer Foundation South Africa):

CHOC’s Guide for Parents
For more info contact:
CHOC National Office
Postnet Suite 105
Privat Bag X260
Houghton 2041
Tel. +27 (861) 113500
national@choc.org.za

Announcements

5th SIOP Asia Conference
In Muscat, Sultanate of Oman
For more information, please contact:
Prof. Zakia Al Lamki
Email: Busaidy8@0mantel.net.om
Or visit: www.infomedweb.com/ourevents/SIOP2008
For parent program contact:
Benson Pau at benson.pau@pkwfoundation.org

April 4-6, 2008
Indo-Pakistan Cancer Kids Cricket Match
Lahore Cricket Stadium, Pakistan
Children with cancer and their siblings from Pakistan and India will ply together with celebrities
For information contact:
CanKinds...KidsCan
Poonam Bagai, D7/7 (Basement) Vasant Vihar,
New Delhi 110059, INDIA
Tel: +91-11-4166-3670/1, Office: +91-98-1152-5745
Fax: +91-11-243-14907
Email: poonambagai@cankidsindia.com
Web Site: www.cankidsindia.com

April 12 -13, 2008
South African and ICCPO Regional Conference:
“Challenges of Childhood Cancer in Africa”
Johannesburg, South Africa.
For more information, visit the CHOC website: www.choc.org.za or contact the organisers on: workshop@choc.org.za

October 2-6, 2008
ICCCPO Annual Meeting together with 40th SIOP-Conference
In Berlin (Germany)
The ICCCPO meeting will again start some days prior to the SIOP meeting (more information will be mailed to ICCCP0 members).
For registration details contact:www.Siop2008.de
Please send your abstracts to SIOP directly: www.siop.nl/abstract
(not to the ICCCP0 secretariat!)
Information on how to write an abstract will be found on our webpage: www.icccpo.org
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