

ICCCPO Newsletter
 Winter 2006
 Volume 13, No. 2
 Published two times
 per year

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Si preferien recibir
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 en Hollanda.

Dear friends,

In September this year, we had a very successful conference in Geneva (Switzerland) with many members attending. You will find some of the presentations of the interesting program in this Newsletter. These and more can be downloaded from our website soon: www.icccpo.org. Many thanks go to Franzi Wursch of the Swiss organization who was responsible for the local planning. It all worked out so very well and the social program was great!

During the Annual General Assembly ICCCPPO accepted 17 new member organizations: 12 full members and 5 associate members. Unfortunately the group in Latvia was removed from the list as we lost contact to the group (no response to our attempts for several years now). This brings our membership to 97 member organizations from 61 countries.

The board reported about the establishment of the "World Child Cancer Foundation" (WCCF), an extremely exciting initiative of ICCCPPO with the objective to improve the access of care for children with cancer in low income countries. WCCF will become the fundraising arm of ICCCPPO. The ICCCPPO General Assembly approved an interim board of WCCF.

Having the ICCCPPO-meeting always along with the SIOP conference gives the important opportunity to network and work with the professionals: doctors, nurses and psychologists of SIOP, but also with WHO and UICC - both based in Geneva. We



had joined sessions with the nurses and psychologists of SIOP and a session with the physicians on "The Inequality of Treatment and Care within Europe." The Executive Committee and other ICCCPPO committees took the chance to meet with the board of SIOP international, the board of the PODC and SIOP Europe.

All in all this was a very productive meeting - but no time to rest: In October, some of us attended the workshop "Cure and Care after Childhood Cancer" in Erice on the Italian island Sicily (more about that in a later issue of our newsletter). And preparations for other meetings have started: Ira Soelistyo is planning a "Regional Meeting for Asia" on Bali, Irina Ban will organize two regional meetings in East-Europe. Christine Wandzura started the preparations for SIOP 2007 in Mumbai (India) and Gerlind Bode had the first negotiation for SIOP 2008 in Berlin (Germany).

Of course we will stay in touch with you via e-mail (so keep us informed of any changes!). And keep sending us your news, share your programs!

We wish you and your organisations a very prosperous New Year,

Gerlind Bode
 Marianne Naafs-Wilstra

Contents

ICCCPO news	2
Survivor's Issues	6
Psychosocial Issues	19
Regional Reports	25
Books	28
Announcements	29
Executive Committee	30

www.icccpo.org

Jean Fabre and Muriel Scibilia

Teaming up between children, medical staff and families: A lesson learned from the front line

(Keynote address ICCCP0/SIOP conference 2006)

There is so much experience gathered in this room that anyone else here could open this leg of the congress. We assume that we have been asked to address this session because we live in the host city to this year's SIOP. So, on behalf of the "indigenous parents", we would like to first extend to all a warm welcome to Geneva.

Child cancer is so overwhelming for everyone concerned that even those who work in hospital structures often do not fully realize what it entails. Therefore, we recognize how difficult it may be for lots of people to identify with what we have to say. But we feel confident to share with you because no one else than another family of a child diagnosed with cancer can understand what it really means to live through that experience.

The reflections we would like to share are not just our own.

They are also those of other parents, of our children, and of some doctors and nurses in various parts of the world who accompanied us through three years of a battle we wished would never have happened.

But before we begin, we want to clarify something. Reviewing our notes last night, we wondered how our reflections might be received by some people here, particularly by the medical staff. We do not want our challenging plea to be mistaken for an unfair judgement. Please understand that when we challenge what is being done in some places and use examples of things that could have been done differently, we do not mean to blame anyone. Our sole purpose is to illustrate the points we wish to make, which otherwise might appear vague and theoretical. We are immensely grateful to all medical staff and want to tell in particular Dr. Pierre Wacker and Dr. Ulya Ozsahin and others who are in this room that we love them and feel much indebted to them. We are utterly conscious of how difficult it is for all those involved in child cancer care to do their respective share of what it takes to tackle the many issues at stake. It is precisely for that reason that we want to invite everyone, from families to medical staff and hospital structures to never stop revisiting what child cancer means and entails, and to nurture the constant desire to do better, no matter how much one has already done.



So - When we look back over our own years of still unfinished battle, what is the single most important lesson we have learnt?

We learnt the vital importance of teaming up. But not any kind of teaming up: we mean teaming up in a way that places the child at the centre, while everyone strives to make things work for every other team member.

In practice, what does that mean, and what comes in the way of achieving this?

Overcoming cancer requires a concerted effort that unites the child, the medical staff, the parents and the rest of the family with an important role played by siblings.

But teaming up comes less naturally than it seems, because the chances are higher that there will be discrepancies of views, or simply different needs, rather than convergence among the three entities.

Interactions between families and medical staff

Cancer puts us all, doctors, nurses and parents, in front of our respective limits. It is a humbling experience that highlights what we do not know as much as it highlights accumulated knowledge.

This is true and can be awfully hard for parents who sometimes have to assess whether the proposed treatment is indeed acceptable – something many parents are confronted with, for example when they are asked to sign an informed consent for a clinical trial.



This is particularly true for the medical staff who are confronted with pathologies, which they cannot be sure will succeed, and sometimes with parents who consult specialists all over the world, surf on the net, raise sharp technical questions, want to complement chemotherapies with all sorts of products that are not part of the protocols, and argue over every step of the treatment.

Care givers are indeed increasingly confronted with a new de-stabilizing reality: families and friends who are ever more and better informed. Without pretending to be competent in paediatric oncology, many parents investigate and compare. Some of them no longer take for granted the truths coming from the medical profession. When this happens, it should not be perceived by medical staff as a lack of trust, but as a positive addition and a legitimate right that should be welcomed and supported.

Our daughter suffered from a Ewing sarcoma on the jaw. She had chemotherapy in Geneva, which was followed by a hospital in Paris. She had surgery in New York. Her jaw had to be removed and reconstructed with a fibula.

After the operation, the surgical pathology report showed insufficient response to the pre-surgery chemotherapy. The strategy proposed by Paris and Geneva was to opt for a massive chemotherapy with stem cells rescue. Given the severe consequences of such treatment, we decided to consult oncologists in several major hospitals in different countries.

This led us to discover that in fact no one knew whether the intensification of chemotherapy could yield better results than prolonging the milder therapy over a longer period of time with less side-effects. We had to take a very difficult decision that placed upon us a huge responsibility at a time when we were vulnerable and needed certainties rather than doubt.

So, child cancer puts doctors and parents in front of equally challenging moments. In such instances, we each have to rise above the inner securities that we have built for ourselves, and open up acknowledging our doubts without feeling threatened. It is extremely difficult for all, but the openness of the team can make an enormous difference.

Before our daughter's surgery, the prospect of removing her jaw was so daunting that we consulted doctors and surgeons all over the world. Most of them told us that it would be devastating for Alice. We were also regularly told that what mattered was to save her life. We were advised not to put our concern for her quality of life on the same level. But we refused that logic and did everything we could to get both. And we thank here the staff of the Geneva Paediatric Oncology who did not discourage us. Identifying the right surgical team made a huge difference.

When parents keep searching and questioning under all circumstances it puts the team to the test! But mutual trust is not blind surrender. It includes recognizing everyone's right (parents and doctors alike) to doubt, question and search for alternatives. Some parents prefer to follow the medical advice they are given without raising questions. Others may choose under certain circumstances to look around and seek additional advice before they give their consent. Both attitudes should be equally accepted and, if need be, options should be discussed calmly in a fully supportive atmosphere. It should also entail that all agree once the decision is taken.

It does not take much to understand how uncomfortable this flexibility can be for physicians, particularly when medical teams are understaffed, and doctors hardly even have time to carry out advanced investigations. Pro-active parents can easily get on the staff's nerves, which in turn can lead to silent hostility that alters the quality of care.

But teaming up should not mean keeping one's questions to oneself for fear of perturbing others. Instead, the team should always be the place to share questions, concerns, doubts, in the same way as we share gratitude and satisfaction.

We acknowledge that we all have duties, not just entitlements. But we also believe parents should never be shy about expressing legitimate concerns. And difficult as it may sometimes be, medical staff should demonstrate unflinching patience and understanding.

Teaming up also means being cohesive in front of the child

After consulting with several private doctors, the mother of a 12 year old boy undergoing chemotherapy had convinced her child at the cost of long discussions to take a series of bio-complements. Shortly afterwards, one of the physicians who was sounding him in the room dismissed these products as useless. Should not such differences of opinion be discussed privately between the physician and the parent instead of having one undermine the credibility of the other in the eyes of the child?

Finding ways of teaming up is the essence of the game, but it requires will, much openness, patience, and discipline. Everyone concerned must adjust to the others, but as parents, because this is all about your child,

you may have to make the biggest effort to make things work even though it is the worst moment in your life.

We would welcome hearing from you other examples from which we could draw together positive recommendations for teaming up better.

As we said earlier: it is vital to team up with and around the child, and to strive to make things work for every team member.

What does placing the child at the heart of it all entail?

One of the implications is that one should grab every possibility of alleviating unnecessary pressures on children. This may complicate the orderly hospital life. But the circumstances are so special that they warrant it.

Adapting the hospital to children versus disciplining children into the hospital

Cancer is a tough experience for children. It is traumatic. It shakes them emotionally as much as physically. On top of it all, they are forced to adapt to the many constraints of hospital life – for days, weeks or months in a row, and repeatedly.

Often, much is done to loosen constraints and to create a supportive and positive atmosphere. But there are major differences from one hospital to another due to habits, space, financial limitations, differing perceptions of what is good and what is not, medical staff viewpoints, characters, rules, management styles, and many other parameters including culture. In each hospital it is worth reviewing practices and structures, and identifying what changes can be introduced.

One of the most spectacular positive initiatives we encountered was around surgery. In New York, surgeons let Alice's sister who was only 16 years old come into the surgery room and help put her sister to sleep. It made a world of difference! Why would such such considerable support to the child be denied elsewhere?

Many simple adjustments can be made. Let us take the case of how days are structured in hospital:

Treatments in haematology and oncology are rigorous. They do not leave much room for individual manoeuvre. They are given round the clock and must be done at precise intervals. And you know, with the pump that whistles through the night, the injections to be made, the blood pressure checks and all that, our daughter was often exhausted at dawn. But hospitals wake up early, and, bingo, that is when a brisk nurse comes into the room. She lets the light in and invites the child to wash herself. Of course, the echo was the regular moaning of a girl begging for a bit more sleeping time.

Our daughter was treated in Europe and in America. On one of the two continents it was readily accepted that she was entitled to sleep as she needed, so long

as she eventually had wash opened her eyes when doctors needed her to. On the other continent, we always had to struggle to get the nurses to respect her sleeping needs. There was even a freshly graduated nurse who made a point of gradually bringing Alice to wake up and wash up on the dot. She proudly built a battle plan over several weeks with deadlines and benchmarks along the way!

We also had to battle with nurses who insisted on being present when Alice washed. This created unproductive tensions for a girl who, at the age of 11, just needed privacy for intimate acts. We found that doctors were a lot more flexible on all these things.

Placing the child at the heart of the teaming up exercise would mean doing one's best to adapt whenever possible the hospital to children rather than disciplining children into the hospital.

The question is: where is the meeting point between the needs and concerns on both sides?

Teaming up means honestly looking on all sides to see where flexibility can be introduced.

So, one has to identify what is essential and what is not. And that can fluctuate according to the phases of treatment or the age of the patient. At a given moment, what becomes essential can be what allows a child to suffer less pain, to overcome grief or to recover self-confidence. It may sometimes clash with the rules and logics of an institution. But, there is a lot to gain by adapting hospitals to children.

- It will be less difficult to administer complex care to a child if the nurse can take the time to delicately un-stick a dressing.
- It will be easier for the child to cope with an invasive act if the nurse or doctor and child have taken the time to talk and exchange at another level.

When care-givers can take time with patients, it can transform a nightmare into a nice moment. After several weeks in hospital due to a pneumonia triggered by aplasia, instead of making our daughter blow into various pieces of apparatus, a physiotherapist turned the sessions into magic moments simply by making her blow soap bubbles in the room.

Attention to details can make a difference

We can talk of the decoration of the room which is not always adapted to the age of the patient. Rooms can be conceived for children and adolescents to bring their posters or other objects. Beyond mere aesthetics, the re-creation of a home atmosphere can alleviate the shame felt by some kids when they are manipulated for certain types of care.

It would be interesting since we have people coming from different places to take a look at how different hospitals are trying to adapt to children.

Impressions from the ICCCPO/SIOP Conference 2006



Instructive practices – whether successes or failures, or mitigated experiences – can be examined with their pros and cons, the extent to which they can be reproduced elsewhere, and what it would take.

So, indeed, we must team up in a way that places the child at the heart of it all. But remember, we stressed that teaming up also means striving to make things work for other team members.

Taking care of parents for a better cure of the child

Parents are often devastated by the news of their child's disease. They also need to restructure their lives. They are overwhelmed and swamped by many additional tasks. They are not prepared. They need guidance. And their morale makes a huge beating difference: if parents do not feel good, it affects the healing.

Supporting parents and families should be a central element of the therapy. Paediatric Oncology departments should therefore take care of parents and families, not just children alone.

Some hospitals make a point of understanding the family context. They offer constant psychological and emotional support to parents and families.

At the hospital in New York, we were regularly reminded that we could make use of the family room and all the facilities it offered - including a computer connection - and there was always a specialist in case we needed to talk during the day. There was also support to solve any practical problem in town to make our life easier.

In contrast, in some other places, attention given to parents is limited to offering anti-depressants when they are given bad news. In that respect, what matters is not just how things are organized. The frame of mind matters just as much.

Help should extend to all sorts of situations

The total collapse of a mother after orthopaedic surgery on her daughter's hip failed and her subsequent inability for some time to be present met with harsh judgement on part of several nurses. She should have been understood by all, and helped.

We were terrified at the prospect of having to break the news to our daughter that her jaw was to be removed and that she might remain disfigured and paralysed.

We could not find in the hospital the professional psychological advice we needed, although we found someone who listened to our fear and dismay.

In fact parents need help in many ways and do not have the time to live through trial and error. Cancer is a seism on families that has consequences long after the pathological conclusion. For example, how to find ways of attending to the needs of siblings?

How can a brother or a sister express that he/she feels neglected when they witness the suffering of their sister or brother? Some keep silent to the point of breathing no more, or getting sick to check that parents still care for them.

Parents should be told what to expect in the whole family, even in the long run, and they should be given tips on what to do and direct access to support in the hospital.

Obsessed by the health of their child, they neglect their own. They should be given a range of ideas on how to take care of themselves, and encouraged by the medical staff to feel free to do it without feeling guilty.

Now, when we say that teaming up putting the child at the heart of it all is essential and that it also means striving to make things work for other team members, one of the unexpected lessons we learnt from the time we spent in hospital is that, paradoxical as it may seem, medical staff needs care too.

Catering towards emotional needs of the medical staff

Nurses – and doctors – are confronted everyday and all day long with suffering children and heavy pathologies. They face multiple sources of stress: from having to perform delicate medical acts with possible severe consequences, to witnessing children's revolts, exposure to mutilation and death, tensions among medical staff, lack of recognition, workloads, the pressures of time and red tape, let alone the problems they encounter in their own private lives.

To cut a long story short, we discovered that this issue had in fact been widely studied by specialists, and that although not all medical personnel are affected, prolonged dedication to oncology care usually leads to levels of stress/burnout above norm scores of other health providers. Nurses in pediatric wards bear the brunt of emotional disturbance mostly through sustained exposure to patients and families, as well as to death.

But we also discovered that internal dynamics in the medical team play a part in generating stress which is equally important, if not more. This warrants an open style leadership – one that encourages internal communication as much as it truly supports all staff members and is ready to implement changes that can improve team performance and individual well-being. Insufficient staffing with qualified personnel is also part of the problem as it places an undue burden on the team.

In order to help children through their battle, caregivers must be relaxed when they step into the room. When a nurse or a doctor is under strain or emotional exhaustion, it is difficult to address calmly and professionally every single situation they encounter. A nurse who feels bad or simply tense is more prone to making a mistake. Further, children "detect" ill-being. After months of confrontation with pain, invasive medical



acts, and sometimes of feeling alone even though families and friends may be around, they become more sensitive and mature. They “know”, even if they cannot put words on it, when medical staffs are burned inside.

When our daughter was diagnosed with cancer, the medical team in Geneva warned us that at some point she was likely to explode and reject everything and everyone. It happened when we came back from New York. After having been in intense pain for so long Alice could not stand being approached by a nurse or a physician. To our utmost surprise, we had to calm down the therapist who had been sent to help our daughter. The therapist was destabilized by Alice's strong rejection, and was unable to understand our daughter and help. We understand today that rather than insensitivity or incompetence, this reaction probably showed that the therapist had reached a saturation level and could not cope anymore.

We guess that you all have anecdotes of difficult moments that are related to staff stress, or of medical staff acting like robots as if de-humanized, which probably meant they were so burned out that it was the only way for them to keep going.

The medical staff needs support too, and ways of letting off steam so as to cope and deliver. Of course, it would be unfair to ask of crushed parents to “take care” of professional care-givers. But understanding their situation helps relate better and re-activate some elements of the much needed team approach.

What parents can do beyond self-awareness and subsequent behaviour adjustment is at two levels.

At the local level, you may wish to draw the attention of the management of the hospital to the inadequacies that need fixing such as shortages of personnel and non-functional infrastructure. You have to do it right so as not to provoke too many negative reactions. We are here in Geneva in the midst of a dialogue with the leadership of the hospital which is not always easy!

At a larger level, we may want to unite our voices and express, as parents and simply as citizens, our concern for the insufficient attention that care-givers receive in our societies, although they play such a precious role.

This consideration leads us towards our conclusion: Moving from the individual towards the universal principle

We tried to identify from our limited experience – one that unfolded in rather privileged places – what are some of the ingredients of a good recipe for teaming up effectively around children with cancer.

Should we leave it to other parents when they are hit by the news that their child has cancer to go through their own experiences, learn some of the same lessons and other, and improvise as best they can to cope with the situation they will find locally?

Or should we build on the knowledge and strength of the Parents Organizations, pool our respective experiences and define together, including with doctors, nurses and children who have been affected and are with us these days, some essential universal principles that SIOF, ICCPO and other partners could adopt and disseminate throughout the world, that would set basic standards for all involved in pediatric cancer ventures?

Some work has already been done in that direction. It is a matter of updating things, incorporating new ideas, and above all making an official and systematic effort at disseminating the agreed upon basic principles throughout all hospitals in the world that treat children with cancer. It is not a battle that one fights alone. It requires the energy, the knowledge, the presence, the efforts, the resources of many people – and it makes a huge difference whether these people act as a true team around the child or as separate individuals.

We know as parents that goodwill from many people does not suffice. Advances cannot be left only to individuals in scattered places with results depending on local goodwill and possibly threatened by evolving local situations.

Obstacles on the way are many. This requires more often than not rising above habits and entrenched attitudes.

It challenges how we think and relate to each others as human beings, as professional colleagues, as doctors and patients, as family members. It calls for setting aside any divide because the life of a child with cancer is a compelling moment of truth that summons us to give our very best. But precisely because it is not easy, because we are human, because we have to learn what works and what not, and because all actors need to be constantly reminded that genuine teaming up is of essence, guidelines from the frontline and a constant structured global sharing of instructive practices could be of tremendous help.

We know that no one better than you – no one better than us all as a team - can accomplish this.

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Renate Pfeifer

Together for the same aim!

(Talk presented at the ICCCP0/SIOP-conference 2006 in Geneva)

What is this common aim, this common purpose?

Let me begin by mentioning that I as a mother know what it means to have a child with cancer. In 1994 our son Stefan was diagnosed with leukaemia and then in 1997 our other son Martin was found to have an osteosarcoma. The therapies were successful, but unfortunately Stefan suffered a relapse in 1998. We also have a healthy daughter. We have thus had the experience of accompanying our sons through three therapies at the Paediatric Oncology Unit in Bonn.

I studied to become a school teacher and my husband is a general physician. Thus I must admit that in many respects we had a better starting position than most other parents. We have been taken seriously from the start and were self-confident enough to discuss things and expect answers to all our questions.

I am often asked: "How could you bear it?" My answer always was: "I and my family were able to bear it because we always had the feeling that we were not fighting alone. There was a whole team supporting us. And - fortunately, our children are alive!"

We all had the same aim: we wanted the boys to get well again and to get over the illness and the therapy with as little damage to body and soul as possible. Martin is badly handicapped in walking and will never be completely well again, and damage to the soul unfortunately cannot be completely avoided.

Thus our aim must be to reduce these adverse side effects as much as possible. These young patients must find their way back into normal life and society, they must understand their own point of view as well as that of others, and they must be able to lead a responsible and enjoyable life on their own.

Our aim must be to ensure their physical and mental health!

Since 1999 I have been a member of the psychosocial team of the Bonn Paediatric Oncology Unit, paid by the parent initiative. My job is to keep young patients in touch with their school. So in a way I have changed to the other side – from the affected mother to the hospital team.



Renate Pfeifer

Our common aim is to ensure physical and mental health!

Successful cooperation is, however, only possible if the will to do so is there and if certain conditions are fulfilled.

First and foremost, the affected parents must be provided with adequate information concerning diagnosis, therapy and prognosis. One cannot work towards a goal without knowing the way there. Of course, every child is different and parents know their child better than anyone else. But the treatment follows strict protocols established by extensive medical experience and thus cannot be very individual. We as parents must recognise the competence of the doctors responsible and must trust them. We have very little to do with the medical decisions. Our desire to do the best for our child cannot, for example, result in giving the child any other medication of our own choice, without having first discussed it with the responsible doctor. We have no knowledge of possible interactions with the chemotherapy.

Unfortunately no one can guarantee that the treatment will be successful. But the parents as well as the child, according to its age, must be made aware of the decisions taken by the doctors. They must trust them completely and not question every step, and at the same time they should support the doctors' decisions, whatever the outcome will be, and, they must accept the fact that for many questions there are no answers or only inadequate ones.

Such a dialogue is an extra strain on the professional team, but the patient will benefit from it. Only thus is cooperation possible, and only thus will the patients and their families be able to come to terms with the illness and all its consequences, in hospital and later on.

What, then, must parents do?

We as parents can be made aware and shown how to support and comfort our child during the therapy and help to lessen the side effects. In this way we can make a very real and substantial contribution to the quality of life of our child. This is our role!

How can we acquire this role? First, it is necessary to understand that, besides the individual needs of the patient, there is also a large fund of collective experience. The initial shock of the diagnosis, the ensuing fear, uncertainty and helplessness, all parents will have these feelings. The reorganisation of family and household as well as daily affairs, these are common to all parents.

Here one can advise and provide help drawn from experience. Parents who have gone through such an ordeal, as well as parent initiatives, are there to give advice and lend a hand. They are able to help very effectively. They are also able to give important advice on any medical questions that have remained unanswered.

Communication is equally important!

Discussions with the responsible doctors and the nurses, with the psycho-social team and other parents: all this will help the newly affected parents to learn to cope and become competent. This makes them fit for the job facing them. In this way parents become increasingly professional in caring for their child in the hospital as well as at home and even if palliative care should become necessary.

Again: communication is the fundamental requirement.

We as a family must learn to cope with the situation, while the professional team must learn to put up with us. We must get to know the individual members of the team, their personalities and their responsibilities. They, on the other hand, must get to know us, our family structure, our sadness as well as what makes us happy. Mutual trust must be established, and that means we have to open minded. Sometimes our privacy will be interfered with. Sometimes decisions have to be made without our consent. Helplessness, despair, even anger can take possession of us. The professional team must be very understanding and must really want to help the family, to respect and trust its members, without any restraints. This is a lot to expect and it isn't always easy. There are usually many points of friction, especially at the beginning.

Both my sons were already adolescents when they became ill. They did not talk much about their illness

and were not always open to people. They were on friendly terms with some members of the team but not with others, and they showed it! For me as mother it wasn't always plain sailing as I wanted to maintain a good atmosphere. But we all felt the honest wish of the entire team to take the boys seriously and consider their individual wishes, and to keep any restrictions to a minimum. An important aspect was the integration of all of us into the therapy. My sons became experts at dosing their medication and managing the infusion machines. Their questions were never taken as signs of distrust. It was even regarded as welcome help when we checked and watched that everything was functioning smoothly. Any difficulties were readily discussed and with growing mutual trust this usually led to an improvement of the situation. No one doubted the competence of the other. This can only be achieved by really open discussions.

One's everyday life revolves around the ward, where one has everything in hand. But as soon as something unexpected happens, if the therapy is not showing the expected results or there is no bone marrow donor available or some other complication sets in, the situation again becomes difficult and has to be mastered anew.

My sons are both alive and well, they are university students, they have friends and socially they are fully integrated. We have returned to everyday life, but nevertheless nothing is as it was. It is very hard to believe that everything will turn out well.

Maintaining the mental stability of patient and family is something which the entire professional team of the hospital takes very seriously. It is not left to the specialized groups. Especially the nurses keep in close contact with the patients and their families. Of all the professionals, they are the ones who know the patients best, their wishes, needs and difficulties. On the other hand, they have to accept that every patient must find his own path through the illness.

Doctors, nurses, psychologists and teachers, they all form a strong team around the parents and patients. But it is important that all team members are aware of their role, that the right team spirit prevails. Patients and parents have a very sensitive antenna in this respect!

What happens when it becomes apparent that the child will not recover?

I myself have experienced this very sad situation with other patients. Each time, I was overcome by a feeling of utter helplessness, I was shocked by the fate of the family and tried to think how I would feel if I were in their position. But these are only theoretical questions and they are of no use in practice.

As a member of the psycho-social team of the hospital I have had to learn anew every day how to deal with difficult situations: approaching another family, helping them during the therapy, not withdrawing when the therapy turns out to be unsuccessful. My own experi-

ences help me sometimes because I know how one feels in such situations. I also know that a family needs time to come to accept the new situation. I have always liked to approach the adolescents personally because my own experiences make me feel particularly close to them.

Above all, there must be mutual respect, for the family and for the professional team. The achievements of the team, both medically and psycho-socially, deserve our highest appreciation and praise.

We as a family have experienced the devoted commitment of our clinic team in a form and to an extent which is rarely found today. We received psycho-social help from all members of the team, not only from the psycho-social group. We always regarded the unit as our ally. If help was possible, then only here, with these people!

Today I, as a member of the psycho-social group, am proud to be a part of this structure. But I have also become aware of how difficult it is to be a real team and to do good and useful work.

It is my aim to strengthen the role of the family within our team and to represent their point of view, because each family must find their own way to proceed - the professionals must sometimes be reminded of this! Our psycho-social team can only offer help, we cannot impose it. And we must also avoid giving the family the feeling that they cannot cope without our help. It is up to us to recognise and implement the natural resources of the families and to offer our help with the necessary respect.

Are there boundaries which must be observed?

Boundaries are often inadvertently crossed - more often in a positive rather than a negative sense - more often involving too much rather than too little help. We should all be able to be professional as well as compassionate. Deep friendships are formed again and again. This must only be allowed to happen with great care. There are parents that allow their child to develop relationships, others fear them.

Such intense experiences usually need to be thoroughly analysed and digested. This does not necessarily require supervision, but it does require one's own critical appraisal as well as the support of the team. This



support should include the full acceptance by the team that such intense relationships can certainly develop. One also needs help to decide on what the most important and correct consequences must be. In this way one learns to cope better next time. Usually one develops a reasonable mode of self-protection.

We - the parents together with the professional team - thus have a common aim, solely directed towards the welfare of the seriously ill child.

I am aware that we have been very lucky with the treatment we received.

Even with this outstanding patient care, something always remains to be done, for example with respect to waiting periods or suboptimal pain relief or palliative care. But we are tackling these problems with increasing success.

One problem, however, remains, namely that the care of young grown-ups with cancer is often catastrophic. Parents of children that have recovered must live with the fear of a possible relapse. That this fear is unfortunately justified, is evident in the daily clinic routine, where we are confronted with late relapses and secondary malignant tumours. What happens then? The outlook is not at all good and the care of young adults with cancer is far behind that of children with cancer.

I would therefore like to appeal to you all: Help us to improve the care of young adults with cancer!

*Renate Pfeifer
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Rosemarie Thomas

A Training Programme for Family Support Workers

(presented at Geneva-Conference, 2006)

Background

This report will describe progress to date with a training programme for Family Support Workers that has recently been implemented by the Child Cancer Foundation in New Zealand.

New Zealand is a long narrow country made up of 2 main islands. There is a population of around 4 million, with a large percentage of the population living in the North Island. The Child Cancer Foundation is the only organisation that provides support specifically for children and families affected by childhood cancer. It is a national organisation made up of 4 Divisions, which in turn support 23 Branches. The mission of the Child Cancer Foundation is:

“No child or their family walking the cancer journey ever feels alone”.

The main focus of the Child Cancer Foundation is the provision of Family Support to children and families affected by childhood cancer, as well as support to the health professionals who care for them. Family Support encompasses a range of emotional, practical and financial support as well as social activities with opportunities to meet families who also walk this journey. The key providers of Family Support are:

- 1) Family Support Coordinators in the Divisions.
- 2) Family Support Workers in the Branches.

The Family Support Coordinators come from a range of backgrounds including parents of children who have had cancer, counsellors, social workers and teachers. They are located at the Family Places which are close to the treatment centres. There is a dual focus of their role:

- 1) Providing support to families while they are at the treatment centre
- 2) Providing training, supervision, mentoring and support to Family Support Workers in the Branches

The Family Support Workers are in a mix of volunteer or paid roles depending on the requirements of their particular Branch for family support. They also come from a range of backgrounds including parents, counsellors and social workers. They provide support to families when they are at home in their Branch. Many of the Family Support Workers have been in their roles for a long time. They started before the Foundation developed an orientation programme so have not had any formal induction or training to their roles provided by

the Foundation but may have attended a variety of different courses in the community. As a result, although it was recognised that they had a wide range of skills and experience, it was also necessary to introduce a training programme which would ensure the safety of:

- 1) Family Support Workers who are providing support to families
- 2) families receiving family support and
- 3) the Child Cancer Foundation as the provider of Family Support services.

This training programme would establish a common baseline of knowledge and skills which is required by Family Support Workers.



Rosemarie Thomas

Implementation – challenges

There are some logistical challenges which we have faced in New Zealand in establishing a training programme for Family Support Workers.

These have included the fact that Family Support Workers are located in Branches throughout New Zealand, covering a wide geographical area. Family Support Workers also have varying levels of availability to attend training as many are volunteers and carry out this work around family commitments and other employment. Of those who are employed their roles are generally part time. This led to the question of how to ensure consistency in training across Divisions as it is not realistic to bring Family Support Workers to one central point on a regular basis.

Other factors that needed to be considered were how to carry out the baseline training programme, where to provide it and who would provide it as well as the potential cost of such a programme.

Potential Benefits

Balanced against the challenges was a consideration of the potential benefits. These included improving the support we offer to families and increasing the knowledge and skills of those delivering family support which would then increase their level of confidence in supporting families. There was also the potential to support parents who are volunteers with training which may assist them in developing a career pathway if they so desired. As well as this there was the opportunity to break down a sense of isolation of Family Support Workers, who may be the only support person in their Branch which in many cases can also be quite remote. As well as creating a sense of being part of a Family Support team there was also the potential to help foster peer support across branches which were in close proximity to each other.

The Training Programme

After consultation with the Family Support Coordinators and Division Managers a national training programme consisting of eighteen modules was agreed upon. It was anticipated that the modules would be delivered as part of a 2 day training programme which would occur twice a year in each Division. Each module has an outline of the training content to be delivered and the expected outcomes. The Training Programme will be coordinated by the Family Support Coordinator for the Division with the support of the Division Manager and the national Family Support Manager. The training modules may be provided by a variety of people including the Family Support Coordinator, the Division Manager and the National Family Support Manager as well as health professionals or contracted specialists where necessary.



The Training Modules

The Training Programme consists of 18 modules which fall broadly into 6 categories as outlined below:

Organisational:

Foundation Structure
Management Guidelines

Family Support Worker
The Family Support Worker Role
Working in team/isolation

Professional Standards
Confidentiality
Ethics
Documentation
Supervision

Psycho Social
Core Interpersonal/Counselling Skills
Stress Management/Selfcare
Grief and Loss
Working with families affected by chronic illness
Working with Families from an Empowerment/
Strengths Based Approach
Benefits and Entitlements

Child/Young person
Child Protection
Childhood Cancer Information

Cultural
Bi culturalism and the Treaty of Waitangi
Multi culturalism

Training Module Outline
Examples of 2 of the training modules are given below:

Training Session Nine - Core Interpersonal /
Counselling Skills

Presenter

This session would normally be facilitated by a social worker, counsellor or trainer with recognised skills in running experiential sessions with a high level of interaction

Topics Covered

- Exercise to consider own personal interactive style
- Establishing rapport
- Active listening skills
- Empathy vs sympathy
- Open vs closed questioning
- Reflecting back
- Summarising

- Paraphrasing
- Reframing
- 'Normalising'
- Use of silence
- Being non-directive
- Dealing with anger, aggression
- Use of body language
- Self disclosure
- Further topics could also include dealing with diversity e.g.
 - Working through an interpreter
 - Working with a family with little English
 - Incorporating cultural sensitivity into interactions
 - Communicating with a visually or hearing impaired person
 - Working with challenging situations or clients

Expected Outcomes

- The Family Support Worker will demonstrate greater insight into the way he/she interacts with others
- The Family Support Worker will develop increased skills in interacting with families
- The Family Support Worker will interact with families in an open, empathetic, non judgmental manner
- The Family Support Worker will demonstrate the ability to deal with more complex interactions in a professional manner

Training Session Thirteen – Working with families from an Empowerment / Strengths Based Approach

Presenter

This session would normally be presented by a counselor, social worker or trainer who is skilled in a strengths based/empowerment approach to working with families

Topics Covered

- Discussion about a strengths based/empowerment approach to working with families
- Building resilience vs creating dependency
- Working with family systems vs enmeshment in the family system
- Discussion of case scenarios

Expected Outcomes

- The Family Support Worker will be able to articulate key points regarding a strengths based/empowerment approach to working with families and demonstrate this in his/her work with families

The Family Support Worker will demonstrate through case studies, internal supervision and 'live supervision' sessions role clarity in his/her relationship with family systems

Progress

This is very much a work in progress. The Training Programme was signed off in March 2006 and two Divisions have already started implementing the programme, one of which will soon run its second training weekend. A third Division is planning its first training programme for late November and members of the fourth Division will be invited to this as there is a close link between these two Divisions.

Positives to Date

Implementation of the programme has so far been positive and enhanced the sense of being part of a Family Support team. It has strengthened the relationship between the Family Support Coordinators and the Family Support Workers and helped to break down a sense of isolation that some workers may feel. It draws on the knowledge and skills within the teams and it has been encouraging to see how open Family Support Workers can be in participating and sharing their perspectives.

It has also created the opportunity for the Family Support Workers to meet health professionals who are working with the families they support and to gain a better understanding of what happens while families are at the treatment centre. As well as this there is the opportunity to draw on and develop community networks.

The important role that the Family Support Workers play is also reinforced through this process and their contribution to family support is acknowledged during the sessions. Ultimately, we are all working together for our common goal of providing the best possible support to children and families affected by childhood cancer.

*Rosemarie Thomas
Child Cancer Foundation, New Zealand*

Notes from the workshops:

Continuity, Transition and Governance in Parent Groups

Organiser: Julian Cutland, with contributions by: Marianne Naafs-Wilstra; Simon Lala; Anders Wollmen; Gerlind Bode

All organisations must go through periods of change and transition. Sometimes these can be traumatic; sometimes they can be planned; sometimes they are forced on the organisation by circumstances.

Parent groups are no exception to this. Old leaders will step back, and new ones will take over. Sometimes these will be parents, and sometimes they will be paid employees.

Sometimes a group will grow and expand because it identifies that there are many needs of the children and families that it wants to satisfy. This may require a major rethink of how the group operates and is managed.

The complete notes on this workshop as well as on the Workshop: Grant Writing (Organized by Val Figliuzzi) at the ICCCPPO Conference, Geneva (Sept 2006) can be found on the ICCCPPO-website: www.icccpo.org



Valuable Tips for Grant Seekers

Organized by Val Figliuzzi

- Allow enough time so others can critique your grant proposal and provide feedback. Modify your proposal as required.
- One person should have the responsibility of writing the proposal, to ensure consistency and continuity.
- Avoid abbreviations unless you have provided the reader with an explanation of what the abbreviation stands for.
- Because of the number of proposals received by funders, your proposal should be typed. In some cases, only typed proposals will be accepted.
- Focus on challenges and opportunities, not insurmountable problems and circumstances.
- Submit a complete application and avoid sending information "under separate cover," with the exception of letters of support.
- If you are not able to provide something the funder has requested, explain why you are not able to submit it.
- Include appropriate and relevant supporting documentation only.
- Send receipts, contract agreements and funding agreements promptly.



Val Figliuzzi

- Ensure your proposal is in the hands of the funder on the due date. If the deadline is March 15 and it falls on a Sunday, your proposal needs to be their hands on Friday, March 13. Try to avoid the last minute dash to the funder's office. Funders often cite missed deadlines as a major reason for declining a grant request.
- Advise your funder immediately of any significant change in your program or project. The reconciliation stage of your project is not the time to tell your funder that they are not getting what they paid for.
- If you receive funding, consider asking a Board member to phone the funder to express your organization's appreciation (if it is permitted). This does wonders for relationship building.

- You can never say “thank you” too often to funders. Keep up the contact!
- If you did not receive funding, and it is permitted, follow up with the funder to determine why they declined to fund your project. Based on the information you receive, you may wish to resubmit.
- If a funder has declined to fund your project, ask for suggestions as to other funders you could approach. Funders have an extensive knowledge of what other funders are doing.
- Invite your funder to your next open house or special event. The more involved your funder is, the more likely you will be able to obtain funding in the future.
- Proofread your work thoroughly, use spell check and consult a thesaurus to avoid repetitious words. Choose words that are benefit-oriented and action-oriented.
- Follow suggested proposal formats. This is particularly crucial for individuals responding to a Request for Proposal.
- Presented your organization's history and mission to demonstrate its overall qualifications and capacity to carry out the work?
- Provided a compelling cover letter that presents a clear overview of your organization and your project?
- Provided relevant background material in accordance with the guidelines?
- Tied the project objectives to the priorities and objectives of the funder?
- Provided plans to promote and publicize the project and the funder?
- Provided a detailed work plan that addresses issues of accountability, project activities, project timetable, partnerships and linkages in a logical and efficient manner to achieve the project's stated goals and objectives?
- Included job descriptions and statements of qualifications for staff if appropriate?
- Prepared a project budget that identifies the costs to be paid for by the funder?

GRANT PROPOSAL CHECKLIST

Your funder may provide you with a grant application checklist. In some cases, you may have to sign this checklist and submit it along with your grant proposal. Always abide by the grant guidelines. Here are some things to consider as you finalize your proposal, assuming they are applicable to your project and acceptable under the terms of the grant program:

Have you, as the proposal writer:

- Obtained a current grant application and related guidelines?
- Spoken to or contacted the designated program officer in connection with your proposed grant submission?
- Verified that you are an eligible organization under the program guidelines submitting a suitable proposal to an appropriate funder?
- Conducted the necessary project research to develop a complete, thorough and compelling proposal?
- Provided all documentation in accordance with the grant guidelines?
- Presented information in a logical and understandable manner?
- Clearly stated feasible goals, objectives and outcomes that respond to a genuine community need and are specific enough to be measured?
- Developed an evaluation plan to document project outcomes?
- Placed your project within the overall context of your organizations mission?
- Submitted a project budget that makes sense, adds up and fairly presents costs?
- Addressed deficits and surpluses in your organization's audited financial statement, as well as monies held in reserve funds?
- Discussed and addressed project sustainability issues?
- Provided relevant quotations, letters of support, questionnaires, surveys, etc.?

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Survivors' Meeting in Geneva



In 2006, The ICCCPO Survivors' Network held a conference in Geneva: Switzerland saw 34 survivors come together from 16 different countries and 18 different organisations; countries represented were Austria (2), Canada (2), England (1), Finland (3), Germany (2), Greece (2), Hong Kong (7), Indonesia (1), Ireland (2), Japan (4), Netherlands (1), New Zealand (2), Philippines (1), Serbia (2), South Korea (1), Sweden (1).

Sessions at this year's conference included joint sessions with the parent's group, joint sessions with the Psychosocial and SIOP groups, sessions with the survivor group only, and a social activity with the survivor group, with a picnic lunch at the edge of lake Geneva, a visit to the Olympic museum, and a boat trip on the lake (via France!) on the way home. Session topics this year included more of a move towards understanding ourselves as leaders and the skills we illustrate in this.

Planning for the 2007 conference in Mumbai India is already underway. We hope to bring even more leaders together from around the world together to share ideas and inspiration and discuss issues applicable to survivors in different areas of the world as well as common issues we all face.

I would like to invite all survivor groups throughout the world to send a delegate to Mumbai 2007 and help strengthen the international network of survivor organisations.

I would also like to invite people who think they have a relevant topic for the survivor workshops or sessions to submit their abstract on the SIOP website; we are keen to expand and strengthen the network of information available at these conferences and worldwide.

And of course, I invite you to contact the network if you are a survivor group we haven't been in touch with, or you are starting up a group in your area. We would like to help by sharing the networks we have created so



far so that you are not alone in your efforts, but have others on the journey with you, who may just well have been there and done what you are trying to do now.

Now is an exciting time for the survivor network and we hope to keep you regularly updated via this newsletter on the networks we have created and improved upon.

If you have any questions or comments for the survivor network, please email me iccsnetwork@gmail.com.

*Prudence Walker-Cuttance
Chairperson
International Childhood Cancer Survivor Network*



Survivors' Issues

Testimonial at Opening Ceremony of the SIOP-Congress in Geneva (2006)

My name is Alice and I am almost 14 years old.

I was just living the ordinary life of an 11 year old girl but the day after my birthday I was told that I had a Ewing sarcoma located on the jaw and that I would have to do a chemotherapy for 12 months. It was hard to believe until I started losing my hair. Doctors were saying "come on, that's only hair" but for an 11 year old girl it's quite hard to put things in perspective.

The second hard step was my surgery in New York. Why New York? Because Geneva told us that the operation was unusual on children and too complicated. There was a risk my face would be disfigured. They proposed to send me to Paris. Fortunately I have incredible parents who, in the meantime, had searched and found one of the best surgeons in the world. With the help of a second surgeon and their team, they saved my face and my life at the same time. They reconstructed my right jaw using my left fibula. When I am 16, the surgery will be completed.

Days before the operation, I didn't want to hear what was going to happen to me. Each time my parents or the doctors tried to tell me something, I did not want to hear. I realize today that for you, doctors and nurses, it is a tough situation. On the one hand, if a child doesn't want to know, you can't force him. But on the other hand, he has to know because he will always hate you if he wakes up with a leg missing or with large scars on his face. A child will never let you enter his world if you try to force your way in. If you do so, he will pay you back.

On the surgery table, I was terrified. I couldn't relax. I mean you know, you really have to trust the doctors who are anaesthetising you to feel relaxed. But how can you put your trust in perfect strangers? Surprisingly the surgeons told me that a member of my family could stay with me in the surgery room until I fell asleep. I chose my elder sister who has been more like a guardian angel to me ever since I was born. The surgeons decided to let her come despite the fact she was only sixteen years old. I felt safer because of her presence. As I fell in love with horses the first time I met one, my sister used my passion to take my mind off hospital. And I can still remember that she said something that made me laugh just before falling asleep.

I would like all the children in the world to be given the same privilege of being authorized to have someone they choose with them in the surgery room.

I had to have rehabilitation for my mouth and leg and I wouldn't have gone through all this without the help of my sister and my parents. The hospital personnel were

so kind. I couldn't eat because it was too painful and disgusting because I had to swallow liquid steak or spinach with a straw. As I hadn't eaten for almost ten days, I was very weak. The doctors didn't want to make a hole in my stomach to feed me so they sent me a nutritionist and together we found something that I liked.

As my leg was too painful, I didn't dare to walk. Finally, the doctors told us to leave the hospital and so we had to handle the situation on our own. I think it was the best way to help us.

This trip to New York could have been my worst memory. But people were so kind and supported me so much, not only at the hospital but even in the streets... - I mean New York is a great city, but New Yorkers don't treat you like a different person even if you are in a wheel chair with a bandage full of blood. They help you and don't stare at you as though you were an oddity that had escaped from the Guggenheim museum.

I got another bad surprise after the treatment: I put on weight very quickly and I had never been informed about that possibility. I'm now trying very hard to return close to the shape I had before chemotherapy.

I also want to tell you that I never could understand why nurses wanted to wake me up at 7am every day. I mean you are not going to have a lot of things to do, so... Furthermore, at night, you can't sleep because of the sounds of the machines, chemo treatment, checking temperature, blood pressure, etc... So, in the morning, I was so exhausted. But I had to fight with nurses who wanted to turn on the light or let the light come in.

We patients don't have any privacy. Everybody comes in and goes out. You don't have time for yourself. I don't think that you want to have an audience when you are taking a shower.

I've just realised a few days ago that I might not have woken up one day. If I had thought just one moment that I could have passed away, I would have changed so many things in my way of thinking and of living my life. Instead of watching TV at the hospital, I would have made something of my days thinking that every one of them was much more precious. But during treatment I was just sure that it was just a bad time to handle and not that every day could have been counted.

Anyway, I'm just starting to realise that I was very lucky because sometimes parents can't afford to go to another country to get better or different treatment. For example, last winter, we went to Singapore for an acupuncture treatment. The efficiency of this treatment is so obvious that I have decided that I want to study acupuncture to cure horses.

I don't think that you realise how important every single sign of support is when you're in hospital - even the simplest. For example, just as Dr. Pierre Wacker used to make me smile against my will when I was grumbling. People were very nice and brave...to put up with a girl like me. Seriously I must say a big thank you to everybody who took care of me, from nurses to doctors to everyone...

This experience has saved and changed my life for ever. I've grown up and I see so many things that people of my age cannot see. I think that before, during and after treatment are 3 really different lives. You don't feel the same, think the same and live the same.

*Alice Fabre
Geneva, 18 November 2006*

Dragana Licina

Does Cancer Stigmatize?



Surviving cancer in childhood - regardless of the possible physical consequences - leaves an emotional imprint, a deep one - just like the Danube which flows through our country. When having been hit by anything so forceful as cancer, which pulls your legs while you try to be calm and believe in recovery, then there comes the question: how can one cope and live with this history as a cancer survivor? The fact is you are not just "like the others", since you had to struggle to stay alive and be lively. Putting yourself into the shoes of the person with an uncommon experience, you realize that the person is not only a name and a surname but somebody with certain characteristics, who is searching for an identity in this world. Surviving cancer is anything but common. A cancer survivor's limits and horizons are simultaneously limited and expanded. This seems a paradox - but it is really like that.

I became sick at the age of eleven and was cured at the age of twelve. These were long months with chemotherapy, radiation, syringes, infusions and other things accompanying the disease. I got so used to syringes that nowadays getting an infusion is just like saying "hello". On the other hand, I was afraid of the different

machines such as X-rays, scanners and MRIs. All those fears and weaknesses that I had to face and overcome as a child appeared to be my teacher in later years. They taught me that these fears and many other problems could be overcome.

There is a prevailing general opinion that a basic fear of a survivor is the fear that the disease might relapse. I believe that two types of fear appear jointly: the one I mentioned already and a the fear of social rejection.

My reaction is: I introduce myself as a cancer survivor. This way I am honest to me as well as to others. I have always felt that this declaration of mine made in public clearly defines my personality: "I survived the cancer in my childhood. Presently, everything is OK; I am cured".

Being a cancer patient does not only imply suffering and pain, drugs and hospitals. In a way, it is also surviving in spirit and mind, finding oneself in one's life, either by slowing down or speeding up. The cancer - even once we manage to get rid of it physically - remains a seal, something that does not let you underestimate life. Quite the opposite, it enhances the joy for it. The disease made a turning point in my life. It has neither changed nor destroyed or scared me. It just stigmatized me (in a positive way?). I am the one that managed to survive the worst; I overcame the worst that could happen in life and I gained the possibility to enjoy life.

If somebody wishes to share the horizons and fears that are still to be overcome, I am here to give you a hand.

*Dragana Licina, a student
Belgrade, March 2006.
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NURDOR - Survivors group
ICCCPO - Survivors Board*

Leora Kuttner

Love and the Relationship Bond between Parent and Child during Cancer Treatment

(excerpt from a presentation at the ICCCP0/SIOP conference 2005 in Vancouver)

Clinicians have avoided addressing the power of love in the healing process. It isn't discussed in literature, textbooks or treatment protocols. Yet we know it plays a significant role in the process of coping and healing. Being loved and loving is hard-wired into humans as part of our evolution, and is a remarkable survival mechanism. Dr John Bowlby, famous for developing the theory of attachment between child and parent, called love the "pinnacle of evolution". Seeking and maintaining close contact provides security, and soothes distress and discomfort. Now we know it also quiets and soothes the nervous system thereby promoting healing.

I'd like to share some thoughts, observations and documentary vignettes about the extraordinary relationship between parents and children – a relationship that becomes even more extraordinary when together they go through the scarily tough, demanding process of cancer treatment. The child-parent relationship has multiple facets, often with an unspoken, deep, intuitive knowledge of one another. The diagnosis and treatment of cancer with its inherent elements of stress, fear of the unknown and greater reliance on one another, can pull parent and child closer together, making their bond stronger and revealing potential for enormous growth and profound wisdom. When the challenge is met, again and again, as treatment continues in its uneven path, the love bond and understanding between parent and child/teen grows deeper in its knowing, reliance and trust, becoming profound.

In a sense I'm talking about how love works in critical times. When someone you love is under threat, deep inner resources are called forth and our hearts open. We become acutely attuned to the other, sensing, observing closely in an effort to understand and determine how best to help. Through this open hearted compassion, the powerful energy of love creates a synergy – combined energies of both parent and child connecting one with the other – to create a life-sustaining, loving support. This synergy is what provides the energy to get through the taxing times.

It's hard to put words to the experience of loving a child, or for a child, loving mother or father and what happens when that love is tested through the crucible experience of the diagnosis of cancer. Rather extraordinary experiences occur. The two documentaries *No Fears No Tears* (1986) and *No Fears No Tears—13 Years Later* (1998)

tell the stories of how eight children, when given the right kind of support by staff and particularly by their parents, become astoundingly competent at making it through the long line of needles, needles and needles. They develop skills in pain and anxiety management, often coached by their parents who themselves have become more skilled in helping their child through these procedures. I'll mention a few vignettes:

In *No Fears, No Tears* (1986), Ann, six year old Lesley's Mom, talks about how important it is for her to concentrate on what is happening to Lesley, to focus and fully be there with her during treatment. She describes how when a wave comes over her that she can't let her concentration affect her own fears, "and I say to myself, 'If this little kid can handle it, then surely I can handle it for a few minutes!' " By putting her own understandable and inevitable fears aside and being fully present for her child, Ann created a safe holding and loving environment in which Lesley could feel, count on and relax within, so that she could cope.

In another section of that documentary Nancy, mother to four-year old Pamela shows how she learned to use a hypnotic technique, The Magic Glove with her daughter for IV access for chemotherapy. She says: "I have to be aware in myself that this is going to work. If I were to approach it saying this isn't going to work, it's just dumb, then it won't work. I have to approach it saying this is going to work and I get in there with her!" Her focused concentration and clear intent is fundamental to the success of their team work. But it is her conviction and loving bond with her daughter that makes her throw herself into the teamwork ensuring that together they do succeed in getting through another Vincristine treatment without tears.

Parents know the world and inform, protect and guide their child. The second documentary *No Fears No Tears – 13 Years Later* shows that this is only the first step. Thirteen years later when the many treatment cycles are



over and the children have returned to their lives, we see them as mature beyond their years, competent, capable and articulate about their experiences, recalling memories of what worked and what didn't – and the meaning they make of it all. The loving, reliable and responsive bond between parent and child is woven throughout their stories. Kelsey at 3 years was angry at having to go through painful treatment, but at 16 teenage Kelsey says with insight and compassion that her Mom did her best, despite "never having had a child with cancer before." The child/teen/ young adult then in reciprocity gives the perfect, 'sweet just right' support and love right back to the parent. Sometimes, when things are at their worst, parents attune to and empathize with their child and a capacity grows, enabling the child to become a well rounded human being and in turn to give back.

In an unexpected turn of events, about ten years after Lesley had completed her treatment, her mother Ann was diagnosed with a rare form of leukemia. We see Lesley, a few years later in the documentary *No Fears, No Tears – 13 Years Later* sitting with her mother Ann relating how worried and scared she was when her

mother was diagnosed with cancer. No-one in the family knew better than Lesley what her mother needed and how to give it. She held her hand, sent energy to her mother and coached her through her treatment. Filled with emotion, Ann says that she now tells everyone that Lesley is her hero!

We can rarely fully answer why things happen the way they do, particularly when we ask the question: "Why did my child get cancer?" – but we do have a choice about how we approach this challenge and how we work together through it, recognizing that the loving attachment between parent and child is a source of remarkable strength, resilience and resource in healing. As Ann so wisely says – it's extraordinary how life works out!

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The video "No Fears no Tears – 13 Years Later: Children coping with pain" by Leora Kuttner (1998) can be ordered at C & W Bookstore (www.bookstore.cw.bc.ca) for the price of 49,95 CAD.\$

Momcilo Jankovic et al.

Psychosocial workshop: "Listening to the dying child"

(SIOP-Congress Oslo, 2004)

Communication with the Dying Child: An Invitation to Listening – A Report of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology*

ABSTRACT

This is the twelfth official document of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology since its creation in 1991. This twelfth document describes the use of direct statements from the children themselves, solicited from parents and physicians, on how children of various ages approached their final days. The parents and professionals who submitted the verbatim case examples were asked to present the children's statements at the seminar as a stimulus for discussion. The children were seeking reassurances from their parents as they faced their own death, talking about a journey to a faraway place where they were going to go after they died and where they would eventually be joined by their parents. The themes are presented, not as exclusive and complete nor as scientifically valid, but solely as a stimulus for SIOP members to pursue in their respective centers and in their own cultural milieus this active "listening" approach in learning from the children themselves the type of concerns they have and the kind of support they are looking for as they enter the terminal phase of their illness.

INTRODUCTION

The previous eleven documents of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology, developed at the annual SIOP meetings were prescriptive in nature, offered as guidelines to be implemented internationally in the treatment of children with cancer (*). This twelfth document in the series was developed, not as a guideline, but as a procedure, an approach to supporting the children after treatment has been judged to be no longer effective and the difficult decision is made to move from the curative to the palliative and terminal phases of care.

What kind of support is the dying child looking for? Research over the years has shown that the great majority of children who enter palliation come to an understanding, from what they see and feel going on around them, that something very serious is happening to them; even the youngest children know at some level that they are dying (1-6). Children with cancer often reach an understanding of what death means for them at an earlier age than their peers and earlier than their level of development would suggest. The dying children

*Proceedings from the Psychosocial Workshop, 36th Annual Meeting of the International Society of Pediatric Oncology (SIOP), Oslo, Norway, September 18, 2004.

- even the younger children whose understanding is still not fully developed -- express their knowledge and emotions about death in various ways, both verbal and non-verbal (7-8).

The objective for this annual meeting of the SIOP Working Committee was to discuss a method for tapping into the children's level of awareness of their impending death, in order to offer them the support they are looking for and ultimately to encourage pediatric oncology professionals throughout the SIOP membership to explore the question in their own cultural milieu.

METHOD

For the 2004 annual SIOP meeting, verbatim case examples were solicited from parents and physicians on how children of various ages approached their final days: what the children said, how the adults in their lives responded, and whether the adult was truly "listening" to the child. This initial attempt was not envisioned as a scientific study but as a stimulus for discussion at the seminar. Sixteen samples were submitted. The physicians and parents who submitted the children's statements were asked to present them at the seminar. The presentations stimulated a very active discussion among the over-100 persons in attendance. What follows is a synopsis of the submitted case examples.

SYNOPSIS

There are several consistent themes that the children expressed in their dying conversations, themes that were raised and discussed at the seminar. They are not raised here as conclusions to a scientific study, which this was not. These themes are a summary of the discussions at the seminar and are presented as working hypotheses for others to pursue in their own "listening" to the statements of the dying child.

- 1) The most common way that the children 10-years-and-under expressed their awareness of their impending death was to talk about a faraway place to which they were going to go after they died. Within their own family's belief system, these children were viewing their death as a journey, not an end. They were looking for reassurance from their parents that they would not be alone while dying, that they would not be alone when they arrived in their faraway place, and that one day their parents would join them:
 - A 4-year-old (f1) talks about her fantasies of what heaven will be like and what she will do when she gets there. She wants to wear her fairy dress to go there with bells on her toes. She does not appear at all distressed or upset or scared throughout the discussion. She wants her doll to come with her and be an angel too.

- An 8-year-old (e1) says "death is like falling asleep, in a nice dream and staying there." He will bring his books and his music and a photo of his grandfather with him so he can recognize him again when he gets there.
 - A 9-year-old (f2) says that it is time to start her journey to heaven, a long and steep climb, but when she gets there it will be worth it. Although "it is sad to climb the stairs alone," she will wait at the top of the stairs to welcome each family member as they arrive.
 - A 10-year-old (a) will go to meet his grandfather in heaven. He will not be alone because his grandfather is already there waiting for him.
- 2) A second theme expressed in the children's conversations is that they did not want to live on in pain. If they had to die, they wanted to die peacefully and without any more hurt:
 - A 7-year-old (b1) talks about no more treatment.
 - A 9-year-old (c1) just wants to be "a nine-year-old kid without cancer. It stinks trying to live with all this sickness."
 - A 10-year-old (g) is angry at the tumor.
 - The older children express the same theme: they want the pain to stop.
 - 3) A third theme mirrored the child-centered view of the children's own role in the family structure and their concerns about whether their parents could go on without them:
 - A 10-year-old (a) asks whether his parents can possibly find the strength to go on without them, without the child's presence and support to sustain the parents.
 - Another 10-year-old (e2) can no longer be the best child in the class and is not ready to die because she does not want to disappoint her parents.
 - A 12-year-old (d2) asks: "Mum, you won't go to pieces when I die, will you?" The girl asks for reassurance that, even though it will be difficult, the parents will be able to move on and cope with their lives without the child.
 - 4) The children in their adolescent years, with a more adult-like understanding of the permanence of death (9), reflected both anger about their impending death and reluctant acceptance of it:
 - A 13-year-old (b2) is "scared" but feels that "it is important to accept and embrace the moment of death."
 - A 14-year-old (h) is depressed and angry, saying a loud "NO!" to those trying to comfort him.
 - A 16-year-old (c2) knows what is going to happen but just does not want to talk about it: "I am not in denial or anything. I just hate talking about it. I'd rather talk about what I would like to be doing now."

CONCLUSION

Participants at the seminar expressed the view that, in “listening” to the child, it is critical to respect the readiness of the child as well as his/her willingness to talk about this experience at a developmental level that is comfortable for the child. The participants discussed their own initial desire as adults to shelter the already suffering children, wanting to protect them from awareness of impending death. But, over time, as they came to realize that children were already aware that something very serious was happening to them, both the parents and the professionals in the group recognized the children’s need to be reassured about their concerns over what would be happening to them.

Addressing these issues not only helps the child, but also helps the parent, even long after the child has died. A recent study of parents, 6-to-9 years after the death of their child, found that both the parents who had had conversations with their child about death and those who talked about the child’s need and concerns without talking directly about the death were able to look back with a sense of having done all that they could in supporting their child through his or her last days. But a large minority of the parents, about one-third, looked back with regret that they had not communicated more fully with their dying child about the child’s impending death and had given false reassurances rather than being attentive to the child’s expressed concerns (10).

In the limited number of examples reviewed in the seminar, the children viewed death from their own young perspective, sharing their philosophy of what was happening to them. Above all else, the children were just asking to be heard, to be listened to, to be reassured as they expressed their concerns.

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The hope is that these examples will stimulate parents, physicians, nurses, and the other health care professionals and volunteers working with the children with cancer to truly “listen” to the children and develop within their own centers a culturally appropriate understanding of what the children are saying about their impending death. By truly listening to what the dying children are telling us, we can learn from them the things that they want to be reassured about.

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Luisa M. Massimo

Narrative medicine in pediatric oncology: its value and role of empathy towards sick children and their families

Introduction

Over the last 15 years the psychological approach known as narrative medicine has gained increasing consent in the medical world, mostly with very sick adult patients who are especially fragile and in need of help. In current practice, conflicting factors are dramatically increasing because sophisticated diagnostic and therapeutic techniques have taken on an important role in the relationship between patient and physician. Sick adolescents and their families want to have a better understanding of the meaning of tests and examinations, of their disease, and of treatment and prognosis. On the other hand, physicians are busier and busier, ever more pressed by bureaucracy, technology, and studies, which means only being able to dedicate a short time to each patient and family. Problems linked to communication, listening ability, and dialog become important, and reach a new identity. Even more than any other type of approach, the narrative approach allows the physician to acquire a deeper knowledge of the patient. There are no questionnaires, no tests, no instruments, but only the communicative ability of the physician who becomes the true friend capable of listening and of helping through comprehension and discussion.

The practice of medicine in the ancient ages, from the Egyptians to the Greeks, cared above all about communication, listening, and information with patients. In recent times sick people and their families require ever more attention from their physicians, who are always too busy to spend time with them. This is the reason for the birth of a new school, called narrative medicine, which can mainly be found in industrialized countries (1-4). Its aims are to teach important techniques of dia-

log and communication. The patient may be physically cured, but he/she still feels unhappy, in trouble, stressed by a lack of certainty, afraid of a relapse of the disease, of late effects, and he/she becomes extremely fragile and incapable of looking at the future optimistically. Therefore, through a real patient-physician alliance, listening and dialog become the first steps towards complete and true cure. During the last few years we have chosen to apply this simple method with our sick children, and especially with our adolescent patients (5,6). Since then, families and children have started seeking us out, not only because we are their physicians, but because they also recognize us as friends who are willing and able to help them. Applying the narrative approach takes time and requires a private office, which, whenever possible, should not be inside the hospital itself.

Narrative and listening technique

The patient's narrative capacity and the physician's listening skills are the two hinges which guide this method applied to medicine. Patients wish to attract the full attention of their physicians, they want to be helped, to be cared for, to have the possibility to talk about their worries, their sufferings. They usually do not like any impersonal forms of investigation, such as questionnaires or structured interviews, but want to be understood, to receive answers to their questions and honest information about the disease, the diagnostic procedures and treatment, including shared, informed consent. We strongly believe that this technique should be studied both at Medical School and during Residency. Nowadays, dialog with patients and their families is difficult even for young graduates, especially if there is bad news to be delivered (7-9). In addition, few teach-

ers at Medical Schools ask their pupils to write about their experience (10,11), in order to increase the value of this technique.

Drawings are the tale of the sick child

Graphic and pictorial communication holds great importance for sick children since this is an area they have easier access to, and that they cultivate through play. This type of activity fulfills their innate need to communicate with themselves and with others. Children express themselves through drawings, using them as a stage to dramatize their needs, wishes, anxieties, and joys. When in hospital, children are afraid, they feel embarrassed around strangers and even parents, especially when the parents are speaking with their caregivers. Children are afraid of making a poor impression and of being rejected by adults, of being considered inadequate and untruthful. Their need for truth and for communication unfolds through artistic expression, and this is the basis of art therapy. The opportunity to express

themselves through drawings is what makes the ill child his/her own therapeutic agent through a self-healing mechanism. This may be further guided so as to lead to an increase in self-esteem, which in turn will lead to both enhancement of their full expressive possibilities and to positive feedback of their self image.

Narrative medicine and the scientific journals

Over the last few years, several outstanding journals have included a section on Narrative medicine, and have dealt with various areas of this topic. Many articles have described the clinical history of patients, others have shared the physicians' experience, thus providing new insight into teaching and into their relationship with ill persons and their families. These articles offer a look at new teaching methods in the Medical Schools, always considering the patient as a person suffering from several difficult problems. With regards to pediatric oncology, this would appear to be especially important in treating adolescents.

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Regional Group Reports

I n M e m o r i a m

On October 26 Neelu Tuli, chairwoman of our member organisation Sahayta in Chandigarh, India, passed away.

Neelu founded Sahayta in 1997, after her sister was diagnosed with cancer.

It is due to her spirit and hard work that Sahayta has become successful in making a difference in the lives of so many families.

Some time ago Neelu herself was diagnosed with cancer. Nonetheless she continued to lead the organization. Her spirit and determination are an inspiration for all.

Our thoughts are with her family and friends.

ICCCPO Board and Newsletter Team



Help for Parents and Children

The Parents Association of Children with Cancer, 'FLOGA' has been functioning for 24 years. In the beginning the Association was nothing but an idea, growing in the mind of the parents who watched their children fight the illness in hospitals that lacked the appropriate equipment and in a social environment that was insufficiently informed and that encountered them suspiciously. In those days, three female doctors made an attempt to establish an Oncological Medical Department at the Children's Hospital 'Paidon A. Kyriakou'.

This medical department inspired in the parents' mind the need to speak for their children's rights - such as psychological care and support and the adequate medical care - with the purpose to acquire them.

What is particular about our Association, is that its main members are volunteer parents, people whose children suffered from cancer at a very young age. Just ordinary people who faced their children's illness with extraordinary courage and endurance. An illness that strongly affected both their lives and their priorities.

FLOGA has been working for 24 years to support families, inform the general public on childhood cancer, establish measures and institutions that improve the conditions for the children and offer a friendly environment in the hospitals so that the children cooperate better with the doctors and better results are achieved concerning their treatment. According to current scientific reports and statistics, 2/3 children with cancer are cured and get back to their previous social environment where they continue their life without any further problems.

Parent-members of our Association offer their help in many ways. Our most important work is The House of Children of FLOGA, a hostel that was created because of the first parent's agony and worries. They came from the province to Athens with their sick children, not knowing where to stay. But, apart from their worries for their child's health, parents should not worry about finding a new home that is safe and warm. Our 'House of Children' is appropriate for children and families. It has teachers and psychologists who help them live in an environment as close as possible to their natural one. In that way, their return to their previous way of living - after treatment has been completed - does not mean a too big change.

The children live in our Hostel as long as they receive medical treatment. The Association has a van to transfer all children safely to their homes.

Our work also provides information for the community on childhood cancer that is conducted through conferences and TV or radio. Another activity is the organization of parties at the Oncological Departments

in the Hospitals, financial contribution to the departments to have them fully equipped with all necessary technical and scientific means. Finally, we pay for the salaries of the nursing staff in case the State cannot pay them. Moreover our Association tries to interfere - with discretion of course - to eliminate bureaucracy so that the parents can stay close to their children. The result is that many parents of children with cancer later became members of our Association and work voluntarily as much as they can. Besides they see that parents whose child once suffered from the same disease are willing to stand by them and help their children.

Last but not least, we offer a program that our children really like. Every summer our Association takes the responsibility of sending cured children to camps in Ireland and France.

These camps address children with serious diseases and mean a great experience to them as they affect their life positively and have an important role in the development of their character. Established and founded by the Paul Newman Institution, these camps accept children with serious illnesses from all European countries every year. There, in a place that could be easily characterized as a Paradise, 20 Greek children come in contact each year with other children who face other illnesses; they find ways to communicate with each other, ways whose basis is their joy and happiness. They look forward to arriving there and when they reach the gate of the Barretstown Camp, they open their eyes wide while the staff of the camp welcomes them and works hard to make them feel like home and experience there the most unforgettable moments. These days will fill their hearts with useful experiences and feelings that cannot be drawn on any picture.

It's not weird what some children said about the activities in the camp: 'I can do it, but my mum would go mad if she saw me like this. When will we come back again?'

The day they have to fly back to Greece, nobody can hold back their tears, even the staff. Everybody is so sentimentally touched and all are crying while the children are getting on the van to go to the airport, holding presents in their hands. After arriving in Greece, they feel the need to describe in detail what they have experienced. However these experiences bear the one and important question: shouldn't Greece offer its children such a camp? Our Association's members are ready to offer their experiences and help those who will undertake the realization of such a program.

FOR FLOGA
GEORGIA CHRISTOFOROU
EXECUTIVE SECRETARY
TRANSLATION FROM THE GREEK TEXT:
SPYRIDOULA CHRISTOFOROU, SURVIVOR

First Pediatric Oncology Palliative Care meeting in Brazil

Palliative care in children with cancer should start from the point of diagnosis and should be a balance priority integrated with upfront therapy directed toward curing the patient. An interdisciplinary team should be present during all therapy. Cross cultural barriers are enormous and children with cancer are still suffering and dying with distressing symptoms. Lack of training at each level of education of all specialities is one important issue.

With this in mind, we organized a meeting in Sao Paulo Brazil, held on October 6th, 7th, 2006. This meeting brought together leading experts in the care of children during the terminal phase as well as experts in providing support to the family during bereavement. There were 83 participants from 6 different Brazilian states and 14 institutions. Nurses, psychologists, paediatricians, oncologists, internal medicine, pain specialists, physical therapists, pharmacists and volunteers attended the 2 day meeting.

Firstly the concept of shifting the focus of care was introduced. Treatment should include comprehensive care starting at diagnosis. Palliative care aimed at relieving symptoms and alleviating suffering should be incorporated during curative treatment all the way through cure and long term follow up or through the bereavement care period. It was emphasised that there is very little research in physical symptoms besides pain at the end of life. It was also pointed out that the lack of acknowledgement and education with limited exposure during medical school and residency training are factors that impair improving the quality of care at the end-of-life.

Secondly, a multidimensional patient assessment, including cultural, social, spiritual, physical, psychologi-

cal, developmental aspects was discussed and an overview of the treatment/management of these symptoms (fatigue, sleep, dyspnea, gastrointestinal) was highlighted.

Pain assessment and treatment was the third step reviewed.

The following day emphasised communication to the patient, family and siblings as well as the care at the moment of death and bereavement. Burnout and withholding/withdrawing therapies such as hydration, nutrition, ventilation and cardiopulmonary resuscitation were also discussed.

There were four sessions on case discussions, presented by different institution representatives. It was a great opportunity to realise that the difficulties faced by most professionals dealing with end-of-life care are similar. Very interesting exchanges among all professionals occurred and the active participation of the audience as well as the experts turned into a unique opportunity for the multidisciplinary educational process proposed.

To end the meeting, programs on end-of-life education were presented (EPEC/ELNEC, USA) to enhance the need for further training.

Communication and listening to the children were the two most important concepts throughout the meeting.

The group felt that a Pediatric Palliative Care Network should be started immediately and that one of the keys to pediatric palliative care is functioning together (as a beautiful symphony) in an interdisciplinary way to attend to the suffering of the patient and family.

*Andréa Y. Kurashima, RN
& Beatriz de Camargo, MD, PhD
(Organizing committee)*

ASHIC

I am highly pleased to inform you that ASHIC Palliative Care Unit was formally inaugurated by one of the leading paediatric doctors who is the National Professor of Bangladesh Dr. M. R. Khan. Unfortunately Dr. M. A. Mannan could not attend the function as he was suddenly diagnosed with Jaundice and needed rest. The function was attended by some 150-invited guests and a large number of media representatives. Our program was highlighted in local T.V. the same evening and good coverage was given in almost all the national

dailies. Our activities started already on from 20th May, 2006. We are sending the social workers to different hospitals in the city to inform the guardians of terminal patients about the services being given by our PCU. It may take a week or so before we start getting patients regularly. I shall keep you informed about the progress in this matter.

*Salma Choudhury
ASHIC, Bangladesh*



Pictures from the 8th Rafi-Memorial Painting competition organized by CLASS

(Bangladesh)



The Mansion for Children with Leukemia

They will never separate from their families

LÖSEV- Health and Education Foundation for Children with Leukemia, which was founded eight years ago by the efforts of three doctors and fathers of two leukemia stricken children, implemented many successful projects in a short time. Our principles, beliefs and diligence led us to open LÖSANTE- Hospital for Children with Leukemia, the School for Children with Leukemia, vocational training courses for our survivors and the mothers of leukemic children and now the Mansion for Children with leukemia.

The Mansion for Children with Leukemia has been commissioned for the first time in Turkey by LÖSEV to ameliorate unfavorable accommodation conditions of families who come to the capital city Ankara and take their first step to their severe struggle during the treatment of their leukemia stricken children.

At the Mansion everything is considered beforehand for the comfort of families. With its 40 bed capacity

and 12 rooms, we have established a new and modern world. We arranged playrooms for children, several activity rooms and workshops for the parents. At the Center, hot water and food service is provided 24 hours a day. The Mansion is in service not only for children treated at our Hospital LÖSANTE, but also to those who are treated in different hospitals. With its homelike and genial atmosphere, family members far away from home are not separate from each other any more nor do leukemic children miss their mothers or fathers during their treatment.

A healthy life is the right of every child. We, as LÖSEV, know that the treatment of childhood leukemia is possible up to 91% when social problems are solved, a sterile environment and healthy nourishment is provided. Our aim is to increase this rate up to 100% and see little faces smile.

P. Gill White, PhD.

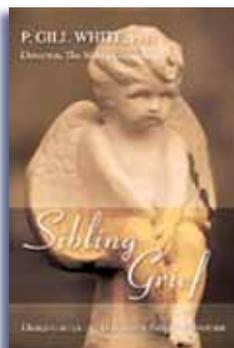
Sibling Grief Healing after the Death of a Sister or Brother,

From the back cover:

Sibling Grief is White's validation of the emotional significance of sibling loss. She draws on clinical experience, research, and wisdom from hundreds of bereaved siblings to explain the five healing tasks specific to sibling grief. White identifies the effects of this profound loss on daily actions and emotions and describes the dream patterns of bereaved siblings, showing how healing is reflected in the dream state. Throughout, she illustrates the long-lasting connection between siblings—a connection that death itself cannot sever. Sibling Grief is a powerful mix of information, personal reflections, and poetry—just what you need to begin your own healing journey.

Sibling Grief is available wherever fine books are sold and online at Amazon: www.amazon.com

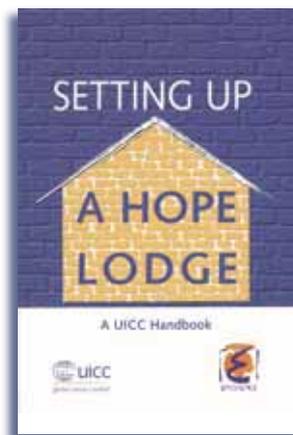
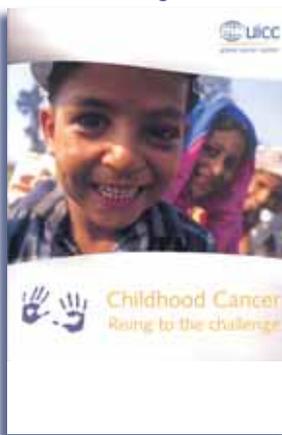
P. Gill White, PhD.
 Director, The Sibling Connection
www.siblingconnection.net



"A Hope Lodge" and "Childhood Cancer - Rising to the challenge"

The International Union Against Cancer (UICC), the world's largest independent, non-profit, non-governmental association of cancer-fighting organisations, hosts a very helpful website, covering subjects from prevention to patient information. Especially helpful are the UICC publications, such as Childhood Cancer - Rising to the Challenge or the handbook Setting Up a Hope Lodge, places of hospitality halfway between hospital and home.

www.uicc.org



Miscellaneous

Are you looking for a supplier of cost-efficient drugs?

The **IDA Foundation** is the world's leading not-for-profit supplier of affordable medicines and medical supplies. Of the available range of over 3,000 quality-assured products 750 are kept in stock for immediate shipment. The foundation offers an extensive variety of indispensable products, ranging from essential medicines to diagnostic equipment. Customers of the IDA Foundation include governmental and non-governmental organisations, public healthcare organizations and wholesalers.

Phone: +31 20 4033051
 Fax: +31 20 4031854
 e-mail: info@idafoundation.org
www.idafoundation.org

Cycling against cancer

Stefan Hörndler, a young German student and a cancer survivor himself, embarked on a tour around the world in August this year. He plans to be on the road for approximately two years - always on his recumbent bike. As of the end of November he is well on his way and has already reached Turkey. He will continue due East, visiting Asia, Australia, New Zealand and the American con-

tinental before heading back to Europe. Stefan Hörndler wants to raise the awareness of childhood cancer with his project and hopes to collect charitable donations for the German Childhood Cancer Foundation.

www.radfahren-gegen-krebs.de

Interesting websites

"Beyond the Cure" gives answers for life after cancer and addresses a wealth of issues that are important to childhood cancer survivors, such as insurance, healthy living, fertility and psychological issues. The site is hosted by The National Children's Cancer Society of St. Louis, Missouri, United States and can be accessed at

www.beyondthecure.org
 or
www.nationalchildrenscancersociety.com

International Childhood Cancer Day on February 15, 2007

Again, there will be a photo contest "Through my eyes" with the theme: the patient at home.

Patients should be asked to take pictures from their home environment (e.g. their own room, their family house, their garden, their family ...). The photos will again be sent to Christine Wandzura, who will integrate them into the next exhibition for the SIOP conference in Mumbai. More information will get to you soon via email.

Announcements

April 5 –7, 2007

ICCCPO Regional Meeting in Bali

The meeting will involve parents, patients, doctors, nurses, psycho-social staff and survivors. It focuses on issues relevant to the Asian region. For more details contact Ira Soelistyo, Email: yoai2008@indosat.net.id

October 29 – November 3, 2007

SIOP and ICCPCO

39th Congress of the International Society of Paediatric Oncology
Mumbai, India
Early Registration Deadline is February 15, 2006 at www.siop.nl
More details: www.siop2007.in
Local Organization Committee: bharataragarwal@iapindia.org
SIOP: secretariat@siop.nl

November 15 -17, 2007

19th Asia Pacific Cancer Conference

Tehran, Iran
If you are interested, contact:
info@apcc-2007.org
www.apcc-2007.org

World Oncology Camp 2007

Sponsored by the American Cancer Society (Great Lakes Division) and the YMCA of Greater Toledo, international camp activities are offered to patients (ages 12-16).

Where: Jackson, Michigan (USA)

When: June 2007.

There are also plans for an international young adult's camp (ages 16 –20).

If you are interested, contact:

Vicki Rakowski (Exec. Vice President) at:

Vicki.Rakowski@cancer.org

FIRST ANNOUNCEMENT

October 1 -6, 2008

SIOP and ICCPCO

40th Congress of the International Society of Paediatric Oncology
Berlin, Germany
More details: www.siop2008.de
Local Organization Committee:
siop2008I@charite.de
SIOP: secretariat@siop.nl

SIOP Asia-2008

will be held in Muscaat, Sultanate of Oman



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 Julian Cutland