

ICCCPO Newsletter

Spring 2004

Volume 11, No. 1

Published three times  
per year

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## Notes from the editors

This year, ICCCP commemoates its tenth anniversary. It was in May of the year 1994 that the statutes of the newly created organization were signed in Valencia (Spain). This event will be celebrated during an international conference – again in Valencia – on May 27 - 29, 2004 (s. also announcements, p. 12). A special celebration of this tenth anniversary will be included in the ICCCP meeting in Oslo (Sept. 16 - 19, 2004). The program of this meeting and the invitation to the AGA will soon be circulated to all groups and can also be found on [www.icccpo.org](http://www.icccpo.org). We are preparing a commemorative booklet reporting on those first ten years, which will go out to all member groups after the Valencia meeting.

This newsletter issue is relatively heavy on words as we were lucky to get the permission for the reprint of several contributions from renowned magazines. But it also includes reports



**Art competition during conference in Sumy (s. p. 18)**

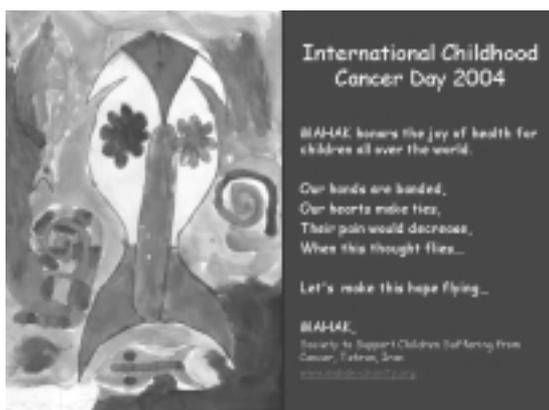
from different groups throughout the ICCCP world – and it is always refreshing to hear about the various activities, mostly reported with a lot of enthusiasm and energetic spirit. We also love to receive pictures showing those events to include them with the texts. Unfortunately, they are often of pure quality and cannot be reproduced. So, don't be too disappointed, if your pictures are not picked up in the newsletter, it is usually simply for technical reasons. Please keep on sending us your contributions.

The International Childhood Cancer Day was celebrated again in many countries with various events. A summary of all these activities will be collected again on a CD and be given to all groups interested in the ICCD. It seems that slowly this date is accepted by the public and the media – and maybe one day also by the UN.

We hope we will meet many of you at any of the up-coming events and will be able to talk and discuss with you all the common issues ICCCP people share.

We would also urge you to inform us immediately of any address changes (name, street, tel-no, email) as it is essential to be updated in order to keep a good communication going. Thank you.

Best greetings to all of you  
Gerlind Bode  
(for the editorial team)



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# Post-Traumatic Growth

**Understanding a New Field of Research:  
An interview with Dr. Mark Chesler by Steven Ungerleider,  
Ph.D. (editor of the Prevention Researcher)**

**Post-traumatic growth is an emerging and rapidly growing field of interest. Dr. Mark Chesler of the University of Michigan, along with his colleagues, Dr. Bradley Zebrack of the University of Southern California, and Dr. Carla Parry of the University of Colorado Health Sciences Center, have been examining the emergence of post-traumatic growth in long-term survivors of childhood cancer. In an effort to understand the concept of post-traumatic growth better, Dr. Chesler has agreed to answer our questions about his exciting new concept.**

**Dr. Ungerleider:  
What is Post-Traumatic-Growth?**

**Dr. Chesler:** Most people are familiar with the concept of post-traumatic stress (PTS). PTS is the recurrent experience of psychological, psychophysical, and/or social symptoms as a result of trauma or crisis. Psychological symptoms can include anxiety, fear, nightmares or hypochondria. Psychophysical symptoms can include sweating upon reminders and faintness upon certain smells associated with the crisis. Social symptoms can include lowered aspirations and school dropout. Post-traumatic stress disorder (PTSD) is a formal psychiatric diagnosis associated with the extreme form of PTS: PTSD and PTS are not interchangeable terms. Post-traumatic growth (PTG), on the other hand, is the experience of expression of positive life change as an outcome of a trauma or life crisis. This does not mean that anyone is "glad that they had cancer", but that they report "having experienced benefits" or "having made something positive out of it."

I highlight "outcome" for two reasons. First, since it is unusual to have before-after measures of people experiencing traumatic events or illnesses, the report of PTG is dependent upon post-hoc reflections by informants. Second, it is dependent upon informants' attributions of growth or change in their life due to the trauma. On both counts, without pre- and post-measures, one must be cautious about whether real change has occurred. As a result, questions about the accuracy or validity of post-hoc reflections of positive change are common.

We sought to assess the validity of our research results regarding PTG in two ways. First, we submitted the tape transcripts of in-depth interviews with survivors of childhood cancer to a panel of pediatric oncology social workers, asking them to categorize informants regarding their post-traumatic psychosocial status: positive growth, return to normal, contin-

ued stress/ struggle, or serious disability/ dysfunction. Second, we submitted a summary of the informants' report of positive growth to an independent panel of survivors of childhood cancer, asking them whether or not they had similar experiences and whether these results were believable.



**Dr. Ungerleider:  
What is the difference between Post-Traumatic growth and resilience?**

**Dr. Chesler:** At the present time, a variety of terms are being introduced to describe the phenomenon of positive coping subsequent to a life crisis or trauma. Given the emerging state of the research in this area, meaningful, agreed-upon, empirically sound distinctions do not yet exist between terms such as PTG, Resilience, Thriving, Benefit Finding, and others. Different scholars use different terms. Several

**Post-traumatic growth is the experience or expression of positive life change as an outcome of a trauma or life crisis.**

(although not by any means universal) suggest that "resilience" describes a "bounce back" or return to prior/normal functioning, while both "thriving" and PTG suggest something gained or a higher level of coping or psychosocial quality of life. One important distinction in this literature is between a threshold or level of coping measure and a measure of growth or positive change.

**Editor: can Post-Traumatic Growth and Post-Traumatic stress occur in the same person, tied to the same event?**

**Dr. Chesler:** Yes, at least according to the theoretical frames and measures currently in use. Post-traumatic growth requires people to be able to remember the struggle associated with the trauma or life crisis, not to deny or ignore it. To remember this pain and uncertainty, to articulate it, and integrate it into one's life, is an essential element in attaining PTG.

The report of such painful memories (and associated psychological, psychophysical and social symptoms) is included in some measures of PTS and may also be taken as a sign of continuing stress.

PTG and PTS are not the same, but some elements of each of them may appear in the same person. My colleagues and I are hoping to test this possibility in the near future.

### **Dr. Ungerleider: What are some of the experiences a youth might have when experiencing PTG?**

**Dr. Chesler:** It is important to remember here that I am not suggesting that most survivors of childhood cancer experience PTG, but some do. Those who do report growth do so in some of the following terms, and this is some of the evidence of PTG:

- New and greater strength (psychological toughness/resilience)
- Greater compassion and empathy for others (for those who have illness/disabilities, for one's parents/siblings)
- Greater psychological/emotional maturity (and greater than their age-peers)
- A recognition of vulnerability and struggle, and a deeper appreciation of life.
- New values and life priorities (often not so materialistic, heightened intimacy in relationships)
- Greater existential or psychospiritual clarity (who am I, what is my purpose in life)

### **Dr. Ungerleider: What capacities or experiences characterize youths who experience Post-Traumatic Growth? Is there a difference between those who develop PTG and PTS, does resiliency play a role, or wealth or other social status factors?**

**Dr. Chesler:** Remember that we are talking about growth or change, not a threshold level of coping or functioning, per se. So it is possible for someone who was at a high level of coping/functioning prior to diagnosis and treatment to still be at a high level of functioning/coping and yet not evidence PTG. And it is possible for someone who was previously at a low level of coping/functioning to show evidence of PTG but still not achieve the same level of functioning/coping as the former person. Consider the somewhat hypothetical case of a young man from an alcoholic and broken/abusive family, with a brother in prison. Prior to being diagnosed with cancer, this young man was ready to drop out of high school and had a poor future trajectory. He reports that during his extended and repeated stays in the hospital he found in the hospital staff the "only loving family I ever had", and from their modelling and support decided to get counselling, gained a GED, is now attending a community college, and has significant professional aspirations. He has grown and attributes his growth in large part to the childhood cancer experience. At the same time, he is still not headed to the elite colleges and the kind of socio-economic status as some other young survivors (who may achieve well but may or may not have experienced growth).

It makes sense to theorize that some pre-existing psychological coping capacity (such as resiliency) is involved in experiencing PTG. We have not assessed such internal psychological states, and how to assess their pre-existing natures and roles presents a substantial research dilemma. This would be a good future research agenda.

It also makes sense to theorize the involvement of certain social status characteristics such as wealth, race/ethnicity, coming from a nuclear family, or having loving family and friends. Our sample was not large enough to provide more than guesses about this. But remember that we are talking about growth, not level, and growth can happen at any level of social status ... although we can assume that higher status families can find more resources to promote growth than can lower status families. Or as a corollary, medical and social service institutions in higher status communities can provide more growth productive resources and support than can institutions in lower status communities.

On the basis of our data, what do we know or suspect that makes a difference? Note that all the following are as much propositions as results; they should be explored and tested further.

Disease/treatment outcome that do not include major physical after-effects (as experienced and reported by the survivors themselves.) For some, an amputation is not major while for others it is. Many survivors of brain tumors do report major treatment after-effects, especially in the cognitive and motoric realm. Thus, both their more serious after-effects and potentially compromised cognitive capacity may affect their ability to experience, integrate and articulate a coherent growth narrative.

The cognitive or developmental capacity to make sense out of the experience and to integrate it into one's life story, essentially the ability to construct and articulate a growth narrative. Thus, being diagnosed/treated at an age when one could understand and make sense of (or have others explain to them) what was happening is essential.

The age of diagnosis and treatment. Some very young survivors have little memory of the trauma or crisis of childhood cancer. If they also have no or minimal after-effects they may have had no subjective crisis to struggle with (or no conscious memory of a struggle) and no story to narrate. Further, survivors who were diagnosed after the age of 20 or so may have already developed a fairly clear identity in their life story, making it more difficult to see major changes or to integrate the cancer experience as a central growth feature of their perhaps well-formed lives. Youngsters and teenagers diagnosed and treated at an age of developmental stage where their identities and life stories are just beginning to be formed may find it more necessary and easier to integrate the cancer experience into this story.

Support from significant others who can provide love, a hopeful message, and a supportive story of the illness experience. This may include parents, medical personnel, friends, and other survivors, among others. Certainly, wise and skilful medical and social service practitioners can make a difference as well – if they are prepared to focus appropriately on growth and not just survival of recovery.

An understanding (provided by others) that the child or young person him/herself was not to blame for the illness nor responsible for the recovery. In the vast majority of cases of childhood cancer we do not know the cause of the disease; it is an accident or act of fate and not a product of personal or familial behavior. Thus, self-blame is irrelevant and does not have to be wrestled with or overcome, as is the case with many adult cancers or other illnesses/conditions or traumatic events.

**Dr. Ungerleider: Is there any evidence that PTG occurs for survivors of other traumatic experiences?**

**Dr. Chesler:** Yes. The concept was developed earlier out of research into the experience of survivors of these conditions, especially those that had considerable support (professional and lay/familial) and who saw, or could be helped to see, that they were not responsible for what had befallen them, reported major growth in their lives.

**Dr. Ungerleider: How extensive is the literature in PTG? And how does one learn how to intervene in ways that promote it?**

**Dr. Chesler:** The literature is sparse but growing rapidly, with investigations into a variety of traumatic situations and practice arenas, sustained in part by the merging tradition of positive psychology. It makes sense that some of the service programs or interventions that are proposed to reduce post-traumatic stress should promote PTG (e.g. family stems approached to coping, support from significant others). But reducing the threat of dysfunction or ameliorating stress is not the same as promoting growth, and other nets of interventions need to be developed. Chief among them may be the effort, early on in treatment, to help survivors develop an understanding of their situation and to integrate their cancer experience in their lives. The development of a coherent narrative, as suggested above, is critical. One often underused resource in this regard is the wisdom and comradery of other survivors of childhood cancer. Not only can these "veterans" share a story and help new survivors piece together their own, but by working together as a group they may create a "narrative community" that can enter the public arena, helping to establish a new culture around childhood cancer.

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This text was first printed in The Prevention Researcher Vol. 10,  
Suppl. December 2003. Reprint here with the kind permission of  
the author and the journal.*

Antonya Cooper

**A journey through cancer –  
parental views, then and now**

At the beginning of 1980, our son Hamish was outwardly a healthy and fun loving boy of 5. By his sixth birthday in February of that year, although he still seemed well, he had occasionally complained of an abdominal pain. We all know that often crops up with young children. I was not unduly concerned, although I discreetly checked for worries at school and took a more frequent interest in his stools. During the following weeks, the tummy aches were mentioned more often and his normally voracious appetite slackened off. Inside me alarm bells started ringing. Early in May, I began what was to prove a long and agonizing series of visits to our local Health Center.

Our own doctor was away on sabbatical leave. As a family, we had not attended our Health Center much until then. He was certainly the only member of the practice who really knew Hamish. Only he could have seen for himself that, in comparison with Hamish's usual appearance, he was indeed not well. The color was fading from his face, the robust body becoming

thinner and more lethargic. He sometimes complained of pains in his thigh, sometimes in his chest or his abdomen. Occasionally he would scream with pain when I hugged him. My son's sparkle was disappearing. Friends and teachers commented on the changes.

During the course of 13 weeks, we consulted five different general practitioners (GPs) (none of them our familiar doctor, he was still away) and a sixth GP on the phone when Hamish ran a particularly high fever in the middle of one night. None of them, while listening most sympathetically, could provide a firm diagnosis. I was repeatedly told that it was probably a "virus" and it should eventually go away. I requested a haemoglobin count. While revealing slight anaemia, it was not considered significant.

At the beginning of July, I could stand it no longer. Something inside me knew my son was seriously ill. With no forthcoming referral from any GP, I made a private appointment with a local pediatrician. The night before I saw him, I wrote down every detail of

my child's case history to that time. Hamish was examined at great length. The pediatrician told me he could find no problem. The choking fear I felt at that moment was almost stifling. I took a deep breath and insisted on two tests. One, a broader spectrum blood screen (in fact I suggested testing for glandular fever) and two, a simple chest x-ray. The latter could surely not offend the pediatrician who was, quite reasonably, keen not to inflict invasive procedure on a child for no apparent symptom – and, incidentally informed me for the first time that Hamish had dextrocardia! Within 24 hours, we received a phone call at home. Hamish's blood erythrocyte sedimentation rate (ESR) was very high. We were advised to admit him immediately to the hospital for investigation.

I know they had a list. It went, I guessed, from common cold to cancer. As each day passed and each intravenous pyelogram (IVP), electrocardiogram (ECG), ultrasound (US) scan, and blood sample was taken I found myself preparing my mind to cope with what I knew would come. On 16 July 1980, I was told that my son had a stage IV neuroblastoma and, without treatment, was likely to survive no longer than 3–4 months. It may be hard to understand, but my tears were of relief – at last someone had recognized our plight!

I wrote this many years ago and have since been closely involved with the Neuroblastoma Society, which this year marks its 20th anniversary. Hamish died on 1 December 1981 and this year I set out to discover what changes there might have been in the experiences of parents then and now. It's one thing to be aware of the progress that may have been made in the world of medical research which is working towards better treatment and eventual cure for this aggressive childhood tumor. I wanted to find out how attitudes now may differ as regard possible improvements in diagnosis and care. Is the average GP any more aware these days of the existence of neuroblastoma? Does that front line medic take the views of the parent more seriously now? I know that the presentation of something as rare as a neuroblastoma may not occur even once in the vocational life of a family doctor. That, however, should ensure that the modern GP is more inclined to refer the patient – it is simply a case of listening to the parent. In the course of my research, I was invited to attend a pediatric oncology clinic. It was deeply disturbing to learn that there are often still long delays between initial presentation at the local Health center and the eventual assessment and diagnosis in the hospital. This is not to suggest that those delays might affect the prognosis, but to highlight the fact that the stresses involved for those families are largely avoidable when more accurate awareness is applied.

Hamish was diagnosed at a regional hospital which, despite being an academic center of medical excellence, had at that time no pediatric oncology unit. He

was referred to a specialist London hospital where he started the offered treatment. Within a very short time, he was clocking up many cannula insertions daily. He got to the outrageous figure of 100 needles before the advent in the United Kingdom (UK) of the Hickman catheter making chemotherapy and blood sampling an infinitely less gruesome trial. Hamish used to mark out of ten to those that used the needles, as if to make their jobs even more testing!

Staff at the specialist hospital began to cope with my hunger for knowledge. It must have been very daunting to be faced, not only with a set of very frightened parents, but a mother who insisted on having every cytotoxic drug's chemical formula and history explained. I needed to be an integral part of the medical team to the extent that I was keen to administer the ketamine that was used to dissociate my child from the bone marrow trephine to be taken. I am assured by a local paediatric oncologist that procedure today is covered by a more conventional anaesthetic.

Continuing "normal" life was then very important to our family and a good example of this was the intention to allow Hamish as much access to school as possible. Although there was a Pediatric Oncology Community Nurse attached to the regional hospital, that role was a rarity compared with the numbers of today's Outreach Nurses. So, in order for Hamish's chums to understand the condition of their friend including an explanation of certain precautions that he may need, I was the one to stand in front of his class and tell them about his disease and show them the Hickman catheter just so they would not find the whole situation frightening, but also so that they would understand that Hamish should not be involved in rough play.

I am sure that the more open communication and media coverage about the whole world of medicine, and cancer in particular, has helped greater sections of the public to a fuller understanding of the issues surrounding a cancer sufferer. In 2003, we have easy access to so many sources of advice and guidance, especially via the internet, that it does not take long to discover the protocols of care that might surround a friend or relation.

Patient comfort was then not easy to achieve. The specialist hospital had eternal laundry and linen problems. Often there were not even enough sheets, blankets or pillows (let alone pillow cases) to go around. Finding this unacceptable when my child was, in any case, being subjected to the sort of treatment that many humans would not put their pets through, we marched on to the ward for our second visit clutching a duvet from home. This, in due course, generated the most enormous row within the hospital administration. Needless to say all members of the hospital staff were only too glad to allow such an invasion of home comfort. The Department of Health and Social Security,

however, represented by a fierce Scottish female who appeared one day at the bottom of Hamish's bed, claimed we were violating safety precautions. Apparently this "downie" (to use the messenger's term), was a fire hazard! Were the children likely to smoke in bed, we wondered? An outspoken Irish surgeon at that time was reported to snort indignantly that the very idea was ridiculous as he had "Never heard of a duck on fire!" Today, most of the children on pediatric oncology wards are cozily covered by duvets if wanted and, in any case, items from home would not be viewed as an insult to the hospital environment.

The existence of a parent's common room and the facilities for producing light refreshments "on the ward" was another rarity. I believe the ability to escape for a supportive chat with another inmate is now well catered for and one should not underestimate the value of such facilities. A few minutes away from the child patient and the sharing of fear and hopes with like-minded people can be very therapeutic. The solidarity gained by the neutral revelations within the confines of such an area is almost always beneficial to those circumstances that encourage others talk; but I was aware that, for me, that was a good way to put some of my concerns into perspective. To discover that parent A was a mother on the breadline with a husband working abroad and four other children in the family or that parent B was a single father whose boss had reacted unsympathetically to the time off work made me immensely grateful that my husband's family business meant that he and I could be together whenever we needed and that our bewildered, 5 year old daughter was being well cared for by a raft of loving relations and friends.

The world's first children's hospice, a place of "respite" for families like ours, was still to be built almost a year after Hamish's death. The vision of sister (then Mother) Frances Dominica of Oxford for such a "home from home", called Helen House, was to change so many approaches to caring for children with life-threatening or life-limiting conditions. Since that world's first in 1982, there are now more than 27 similar places, just in the UK, with more being developed as I write. In 3 months time, there will be another "first" in Oxford – a building called Douglas House for young people aged between 18 and 40 years. Progress in medicine has succeeded in extending the lives of some of those who 20 or more years ago were not expected to survive childhood.

Pain control, thankfully, has advanced most of all since those hyper-cautious days in the early 1980s. Many health professionals, especially those away from the specialty centers, had the specter of the "Dr. Arthur case"\* sitting on their shoulders. Some of them argued for the possibility to addiction to opiates. Here we were, witnessing a child in unimaginably pain who was almost certainly going to die of cancer and a medical

person dared to suggest that the reason for not providing (in my pitiful parental view) enough pain control was a concern for diamorphine dependency! Again I refer to the treatment of animals. A self-respecting veterinary surgeon would no sooner inflict on or allow pain in an animal than cut off their own arm. Today we have patient-administered syringe drivers to keep abreast of pain levels. There are also transdermal patches releasing Fentanyl. The whole ethos of palliative care is part of modern medicine. My own experience of postoperative medication assures me of a very different emphasis on the suppression of pain nowadays.

**These are my hopes for the future.**

I wish all medical personnel to regard any parent of any sick child as a valuable member of the total caring team. Even those parents who give an impression of not wholly grasping the concept of treatment, protocol, medication or medical procedure, need the empathy of the doctors, nurses, social workers and any attendant care-givers. The ability to stand alongside, even when all therapy is failing, to be honest in the face of the inevitable or even the likely, is lovingly-given care at its most complete.

I wish that no parent should ever feel the need to become assertive in order to be heard. Too often we still learn that parents feel they are regarded as "neurotic" when attempting to bring a concern to the notice of someone with the power to comprehend.

I wish that all those well-intentioned instructive leaflets or booklets, so meticulously produced by organizations for the information of frightened and suffering parents, should not be hiding in some cupboard never to see the light of day! Hand them out!

I wish that those who would most benefit from hearing the frustrations of some parents should be shut in the same room and forced to listen. Those who really care do not need converting. There are many of us who are available and willing to help health professionals to better understand the needs of the families involved with life-threatening conditions. Please use us as sounding boards, speakers, broadcasters, and writers. The barrier I most fear is the resounding clang of the division that separates some health professionals from patients and families. You can see the "curtain come down" across the eyes of the medical person. The explanation might be that they feel the need for a wholly objective approach to protect the efficiency of their medical judgments, let alone their own emotions. But that is not an excuse, and greater progress will be made in their chosen vocation if the professional communication is fully two-way with the sufferers. Over the 21 years since the death of my son Hamish, I have witnessed the best forms of support, care, guidance and healing given by those willing to expose their humanity and "share" the experience.

\*Dr. Arthur, a highly respected paediatrician, was accused, and acquitted, of blatant active euthanasia. In 1980, a Downs syndrome baby in his care was rejected by the mother soon after birth. Dr. Arthur prescribed a sedative designed to stop the baby seeking sustenance. The child was given only water and died within 3 days.

## Acknowledgments

I would like to thank the following for their encouragement and their help in my update research: Chris Mitchell, Denise Tritton, Hannah, Mike Stevens, Judith Armstrong, Annabel Foot, Jon Pritchard, A.R.C. and R.C.T.J.

*Antonya Cooper*  
This article was first published in the *European Journal of Cancer (EJC)*, Nov. 2003, Vol. 38, No. 17 and is reprinted here with the kind permission of the journal and the author.

Renate Pfeifer

# Childhood Cancer – a Mother's Retrospective



In March 1994, when our son Stefan was 13 years of age, he was diagnosed with acute lymphoblastic leukaemia (ALL). He was treated with chemotherapy according to the BFM-92 protocol in the Children's University Hospital in Bonn, Germany, followed by brain irradiation and maintenance therapy. He recovered slowly from the side-effects of the disease and its treatment and life seemed to be "normal" again, when in November 1997, we were shocked again by the news that our son Martin, then aged 18, was diagnosed with osteosarcoma of the pelvis. He too received chemotherapy, was operated upon and received further courses of chemotherapy according to the COSS-96 Protocol. One half of his pelvis and one hip joint had to be removed. As a result, he is now handicapped, walks with a severe limp, cannot run or cycle and needs special cushions for sitting. However, he has learned to cope with the deficiencies relatively well.

Only a year later, in December 1998, Stefan, then 18 years old, had a relapse of his ALL, which was treated with the more intensive relapse therapy and again brain irradiation and maintenance therapy.

Today, both our sons are well integrated in their social environment and are presently attending university: one is at medical school while the other studies computer science. You can imagine that we all hope that cancer is now a part of our past. It is not very common that two children in a family – we also have a daughter who is now 20 years old – are affected by this dreadful disease and our experience should not panic other parents. We would like to illustrate here our personal experiences and how we learnt to cope.

At the end of Stefan's first period of treatment, I started to get involved in the local parent initiative for children with cancer at the University Hospital in Bonn, as well as in the national organization of all parent initiatives in Germany, which shares its office with the local group. Today, I coordinate a school project designed and sponsored by the local parent initiative that links the patients with their home school via a specific 'Intranet'. School-aged patients, when they come to the ward, are equipped with a laptop with internet access which enables them to participate in their individual classroom teaching. We also provide the server and a camera in the classrooms of the home school, instruct the teachers and the other classmates who are generally very enthusiastic about this way of being able to communicate with the student in hospital. Thus, the patients are closely connected to their classmates and teachers, keep up with their curriculum and are informed about all school events.

The diagnosis 'childhood cancer' was a great shock for us, especially as it hit our family three times. Retrospectively, we can say we were lucky to live in a town with a qualified paediatric cancer unit where we got the proper treatment and excellent care. We were thoroughly informed about all aspects of the disease and its treatment. We got answers to almost all our questions – of course not the one "why us?", which is still on our minds even though we, the parents, underwent genetic counselling. During the treatment period, doctors and nurses always found the time to talk to us, explained each new step and all the medication involved. Most of the time we were prepared for all the expected side effects and the reasons why these or those measures had to be taken. Our sons were also well informed, which certainly increased their compliance. Both had a port-a-cath implanted which eased the application of the necessary infusions. They always knew the doses of each medication and were able to control the infusion pumps themselves which gave them independence and a sense of responsibility.

When I met with parents from other hospitals I was amazed how much I knew about the diseases of my sons compared to these other parents. Of course, some medical background – my husband is a general practitioner – helped. But frankly, most of the knowledge I

acquired about the disease I got on the ward and from my work with the 'parent initiative'. We felt that this knowledge and understanding helped us in any decision making and in the support of our sons as patients. We also realized that honest information was very important for our sons – and any other patient – to be able to endure the treatment procedures, with all their implications.

When we were in the hospital for the first time, we were appalled about the situation on the ward. It needed renovation badly: there were only two bathrooms for 16 beds, large rooms with four or more beds, no privacy – especially uncomfortable for teenage patients! The University budget had no finances for extensive renovations. So the 'parent initiative' took action and raised enough money for the renovation of the old ward and the building of a new annexe which added double the space to the Unit. Now we can proudly present a modern set-up equipped for all necessary treatment modalities: comfortable single or double bed rooms with private bathrooms, isolation rooms for stem cell transplantation, a spacious play-room which at night times is also a meeting room for the teenagers, a meeting room with a kitchenette for parents, two modern treatment rooms, a fully equipped outpatient unit with day beds and the stem cell separation equipment, rooms for the psychosocial staff and much more. In short, the situation has changed much for the better.

In spite of the outward appearance of the Unit we experienced very professional medical care from the very beginning, and this gave us confidence in all decisions that had to be made. The well-trained nurses on the ward are an essential part of the team. They are the first ones to notice any changes in the patients' behaviour or appearance and are able to react in an appropriate manner. They are not only doing their medical routine but also in comforting the patients, taking their fears seriously and yielding to their likes and dislikes as much as possible, they help in so many other ways.

Psychosocial support is an integral part of the treatment. Two psychologists, a social worker and a child-care worker take care of the entire family from day one. They may help extensively for example in all legal and financial aspects, or support the family only when needed. We – apparently – had a well functioning family and needed only very sporadic support, but we know of many families or especially single parents who fortunately got a lot of help throughout the course of intensive treatment and even later on. Today the Unit also has a homecare team: four nurses who visit the families at home for applying care that would have to be done in the clinic. This kind of help is invaluable especially for terminally ill children, who can be treated in the home situation.

With each new period of hospitalisation, our family had to yield to the unexpected situation. The third time around we were already experienced, though the treatment was much more intensive and our fears – realistically – much more profound. As we live not far from the hospital we were able to take 'shifts' in visiting the patient – we, the parents, but also the siblings, school friends and girlfriends. Often the whole family gathered around the bed but we also felt it very important to leave the siblings and friends alone with each other at times. Thus, they could communicate with each other about worries they may have wanted to hide from us, their parents. However most important, all of them were well informed at all times.

We are grateful for the recent developments in the treatment of childhood cancer. The therapies, although more intensive these days, are more tolerable with more effective supportive care, especially the effective control of nausea and vomiting. We know from former patients how much more difficult the therapy would have been without these advances.

For Stefan, the irradiation and maintenance therapy was each time a frustrating burden. Both times he experienced severe side effects which hampered him as he wanted to be back to normal life as quickly as possible. Instead he felt very tired, often dizzy and sick. But his social surroundings – friends, family – backed him up as much as possible and he finished school with good grades. It hurt him very much when he realized that he could not continue with his favourite sport, tennis, as his backbone is damaged due to the disease. He started to invest his energy in music instead and is now a very passionate drummer, plays in different bands – for fun and for money!

Martin's therapy was different, especially with the invasive operation – which was done in another city – then followed by courses of chemotherapy: one week in hospital, two weeks at home. In between another operation: lung metastases had to be removed. He needed much more physical care as he was in a cast from the waist down for most of with the treatment time. And when the cast was removed he had to learn walking with part of his hip missing and one leg shorter than the other – a young adult who needed help like a baby! It was not easy for him to accept this help from any of us, let alone the nurses. Driven by his deep desire to become independent again as quickly as possible he trained his body mercilessly. As soon as possible, he took driving lessons and got his driver's licence. We bought him a small car and thus helped him take another step towards independence. Nowadays, he lives in another city, has a girl friend and hopefully will finish his studies soon.

Both our sons were teenagers, almost young adults, when they were diagnosed with cancer. Nevertheless, they were treated on a pediatric ward, which was good. We felt that the care and treatment for these

kinds of diseases were in the 'best hands' on this ward. The boys were always respected as individuals with rights of their own in the decision-making process. Throughout the treatment, they are often enough dependent on help from others – nurses, parents, siblings. In turn we all respected their needs and wishes in order to give them back their lost independence and a sense of responsibility for their own fate

In Germany, the family of a child with cancer is entitled to a four week long rehabilitation period, paid by the general health insurance, in especially qualified centers. We decided not to take advantage of this possibility but took an extended vacation instead.

### **Wishes for the future**

All parents and patients would like to see survival rates increase to 100%. It would be great if every child with cancer had the chance to survive. Meanwhile, the fear of a possible relapse is hovering over us all like a Damocles sword.

In the time that we were actively involved as parents of patients much has changed for the better in the treatment procedures. To give a few examples, there is better supportive care and pain control, control of nausea and vomiting has improved and anaes-

thesia is now applied for painful procedures. It is our wish that the quality of care will not suffer from the expected budget costs in our health system. We would also suggest a better coordination among all of the clinics involved in the treatment. This would cut down on waiting times and would certainly enhance the efficiency.

Our sons would have liked a set-up that was more suitable for teenagers or young adults. Although they preferred the treatment in the paediatric Unit with the expertise of the paediatric oncologists, they would have liked to have a place of their own on the ward, a room for teenagers, a retreat where patients of their age group could gather and maybe listen to 'their' music or play 'their' games or just talk. Of course, they would have preferred shorter periods in hospital and, if possible a shorter treatment time over all – and, most of all, no pain. They still hope for more understanding among their peers or in their social environment for the disease and its long-term effects.

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*This article was first published in the European Journal of Cancer (EJC), Nov. 2003, Vol. 38, No. 17 and is reprinted here with the kind permission of the journal and the author.*

Maria Trifonidis

## **The parent during the final stage**

I think that people who came through life without having become parents or not having felt parenthood, are not aware of the depth and the extension of human feelings, which constitute the real essence of life.

For all that I am going to say I have had no recourse from any bibliography. It is a statement of the soul. A common soul, that of my husband and myself, also that of the parents of Theodora and of Christos, that of the parents of Michael and Steve and of so many other parents we encountered along the way.

### **The final stage**

Having to give a definition as to what the Final Stage is, I would specify that period of time which begins following the last relapse until the last moment.

### **The time period between the diagnosis and the relapse**

A certain period of time has lapsed since the diagnosis. The parent has pulled himself together, all the bits and pieces of a broken heart and, as far as this is possible, has restarted the course of life and family. With all the strength at his disposal, he focuses all actions and interests on one and only point: this specific child. He is being informed of the sickness and of what he is

expected to do, he follows the doctor's advice faithfully, reads everything pertaining to this matter that he may come across and tends to believe that he has become the healer of "that and only sickness".

Subconsciously he has already engaged himself in a phase of "preparation" to meet the final stage, without his knowing it or his accepting it. If all turns out well, this preparation, which will precede, will intensify the feeling of victory and relief.

If however, things do not turn out as expected, such preparation will prove even more substantial. Where a subsequent relapse seems the last limit of endurance, the distressed parent ascertains with surprise that he can still endure, that he is still there to be confronted with, because somewhere in the back of his mind he has been prepared for such an outcome and he expected it.

### **The relapse**

The time of the relapse contains less surprise than insupportable death pain.

The parent's attention is not at this time conveyed in efforts to learn, to ask, to pull his shattered self together.

He is now aware of everything he could amass to learn about the "illness", the "relapse", the "possibili-

ties". Hope is reluctant to follow him anymore. He is now face to face with the truth. He himself, the possibilities and all doors closed. The events, the medical examinations, the tomographies break him to pieces. Belief in a better outcome, which hitherto was his living breath of air, has now abandoned him.

He has to relocate his attitude towards the enemy. The enemy is in the advance, the battle, however, has to be continued. A change of tactic is required. The moment is crucial. He either:

- Conforms and cooperates with the doctors or he reacts and considers them responsible for the relapse
- He sometimes visits the various medical centers overseas
- He often runs to religion and visits one monastery after the other
- He also turns to and seeks other methods of therapies and remedies
- But there are also those who leave the battle and simply expect the inevitable

Though nature does not provide everybody with the same potential, the same amount of knowledge, or give the same opportunities, it expects from everybody the same capabilities, when it allows everybody to face the same problem and to feel the same pain.

### After the relapse

The presence of our child, after the conscious acceptance that this will be "temporary" becomes particularly valuable. It suddenly assumes overwhelming proportions and, as long as the parent lives in the company of his child, he feels so overflowing of his presence, as no parent of a healthy child would ever feel.

Within this very short lapse of time, the parent will concentrate the events, feelings and experiences of a whole lifetime. Every moment is special, every hour is of importance.

These are the moments, these are the hours, which are to become our remembrance to fill our lives ever after and to keep our child alive in the inner self for ever.

Our children, being transformed within this period of time into little "Gods" in our hands, enrich our life with feelings unknown to us up to this moment. Joys to be experienced at this stage of our life, which I would characterize as a "waiting" stage, are unique.

At this period of time we sip insatiably the presence of our children, we make every moment worth living, we stand abreast, we assist.

Our existence on earth has acquired a decisive element, a clear destination and meaning.

We stop the lapse of time. Because at this stage we can now prolong the days, extend the hours, live now only in the present, leaving the dim future lingering thereafter, whenever it comes.

### Medical and paramedical personnel

All medical and paramedical personnel ought at this time to have a distinctive presence instead of disappearing, considering that their assistance in offering any therapy is of no avail. They should forget to act only from a sheer professional aspect and should stand by with kindness, clarity, politeness, earnestness, patience and respect opposite the psychological tumult of the parental soul. The child is still here. During the doctors' morning visit, no change should make itself perceptible.

The final stage child does not need doctors with sheer professionalism and rigid behaviour. A doctor of this delineation could become a microbiologist, a dentist, an obstetrician or whatever else.

Here we are dealing with a child leaving us. In such a case the contact of parent and the child with the doctor is on an everyday basis. Here a relationship of dependability is being built. The doctor's presence will play a catalytic part in the final stage quality of life.

The doctor's presence will assume a place of dominance in the life of the whole family.

At this stage the parent has a complete need of assertion that he has done whatever was correct and precise. The future life of the parent and the family as a whole, will depend greatly on the doctor's stance and the assurances he extends.

The oncologists, hematologists and pediatricians should follow special courses in psychology, most of all they ought to possess inborn humane traits.

### Pain

Pain is the most basic element in defining this period of time. If the child is in pain, everything the parent endeavors to build comes to pieces. The distressed parent has by now learnt to accept everything, even the approaching end. But he is incapable of sustaining his child's being in pain. All forces, gathered with so much effort so far, are abandoning him. Allow me to refer particularly to the issue of pain in stressing the point that science and the medical staff have not as yet focused their interest thereon as much as they ought to, and the cases of children suffering pain are of a quite large number. It is, at the very least, unacceptable in our times to let children suffer pain. The science of the 21st century owes these children at least such a relief.

### Siblings

Siblings, amidst an avalanche of events, remain bystanders of the evolving situation around them, sometimes in silence, sometimes reacting and creating problems, in order to attract our attention, since there is no other way to achieve it.

We parents in our anguish, forget that all children have the same rights. We inflict on them, without our

knowing it, fears, guilt, remorse, fatigue and misery. Their tender childhood years will always bear the marks of the era and the impact thereon, whether positive or negative, will be unavoidable. The best way to face the situation is to involve them in our "problem". But which parent can think and act rationally under the burden of so many feelings and events?

What we all should and can do at the very least, is, I believe, remember now and then to ask to be excused by our other children and request their understanding for our partial behavior, while at the same time providing the necessary explanations to relieve them of their remorse and fears.

At least that is what I tried to do a very few times of course, and I believe that today I have a son with no psychological problems, while establishing a strong and tight relationship with him.

### **Grandparents, uncles and aunts, close friends**

Pain for 24 hours a day is just too much for us parents. However, the persons close to us suffer with us too and their assistance is valuable to us. Their being present at the threshold of our pain and lending us a shoulder for our tears make some of us – I wish I could say all of us – luckier than others.

### **Wider environment, neighbors, far relatives and friends**

Communication with all these groups of persons may gather for the parents assertions and experiences concerning human nature, which few professional scholars may proclaim to possess.

Fears denude the wider human environment and the parent, and the child as well, are often compelled to face pity rather than love, curiosity than interest, mercilessness and indifference than assistance, sometimes even racism.

It is better for the wider environment to remain "wide". Any effort at conciliation will prove to be at least "false" in my opinion, creating rather than solving problems for the parents and the child alike.

### **The School**

It may be the case that psychologists recommend at this stage – depending on the condition of course, that the physical state of the child still allows it – a return to school.

The child must be free at least to follow its wishes, without intrusions.

The child is entitled to determine its life and do what it really wishes to do. If however, the child decides to follow classes at school, the parent is called to face additional problems regarding the smooth rehabilitation of the child at school and the problems of illnesses, low leukocytes etc.

### **Home Care**

The child's right to remain within its "private quarters" during the final stage period is sacred. The child, if it so wishes, may at this stage have required all medical care at home. It would be ideal for a unit to exist constituting doctors, paramedical personnel and psychologists to visit and care for the child at home.

The parents will then be able to offer all their loving care to the child and enjoy moments of peace and serenity alone with their child, away from the hospital's unease, which distract their attention.

### **Financial contentedness**

The parent at this stage is not capable of working, while the child's needs, as well as those of the family, are increasing.

His wish to provide every possible comfort and the best living conditions that exist to his child is impressively moving.

If there is no money at hand or other ways of providing a decent way of life to the child at this final stage, the parent undertakes an additional burden. When not in a position to meet the child's requirements, he is brought face to face with sentiments of absolute distress.

### **The last days**

The parents have now only one point of interest. Wars, fires, revolutions, all those events characterized by other people as "news" do not reach his ears. His other children do not reach his ears. His other children do not persist in his thoughts, the remaining family has no need of him.

At this period of time, this child is here. He desperately endeavors to improve the living conditions. To alleviate pain from the child, if there is any, to make the child smile, to prolong lifetime.

He reacts by shouting, crying or staying mute. He has gone so far as to be capable of living by allowing only part of his head and mind to operate. His thoughts are full of what he wishes to do or is able to do. And he persists. Human nature has by now summoned all the defense mechanisms at its disposal because, in the end, one can endure to the extent one is required to endure.

### **The final moment**

The last moment is the beginning of another, the aftermath of a struggle, which will follow the parent till his own final moment.

### **The aftermath**

The loss is ours, the grief is ours, the child is ours. Time has come for us to mourn as long as we wish to. Time has come for us to accept that we suffer. Now, after a long time, we have "the time" to cry. The time

has come for us to be free, free to mourn and grieve, to bleed, to dissolve the material part of ourselves of effort and pain.

The assistance extended to us by our close friends and relatives should bear the essence of our own requirements and not that of their personal beliefs as to what would be right or wrong for us.

We sometimes cry as much as we can. Sometimes we stay still, confined to our inner self and sometimes we engage in endless talk. The idea of a second life, the continuation of man's spiritual nature, sustains us. Certain dreams, mixed with fantasies, between awakeness and sleep, provide us with a task.

From one moment to the next, we find ourselves with empty hands. The endless days and nights over the patient's pillow are left vacant. We do not prepare dinner, we do not wash his clothes, we do not give medication on time and our mind does not have to cope any more with leukocytes and red blood cells for the day. Our continuous effort to find more time has no response, no result. Our everyday time has switched from being too short to being endless. Our remaining children do not bother us. Our family is so distant.

### **Time**

"Time" brought us nearer to the end, and the terminating hour.

Time snatched us from our own mother's arms, made parents out of us, deprived us of our children and we now await for it to lay out our life in the future and heal our traumas.

### **Today, after many years**

My son, my husband and myself, the family, friends, work at the parents association for children with cancer, shopping, summer holidays etc. – this is all very normal ...

### **But also:**

Moments of loneliness, meditation and remembrances. Moments when the key of the heart opens the door letting reminiscences overflow as a torrent into every corner of my life. Moments when I re-live everything I have most lovingly treasured and kept dearly in the depths of my soul and I emerge from there renewed and ready to go forth.

Today, 18 years after my Alexandra passed away, I consider myself lucky for having even for only six years filled my hands with this child and offered to her my adoration, this child, which brought to my life with so many never before experienced and deeply moving feelings, and taught us what braveness and dignity means.

*Maria Trifonidis  
Floga  
Parent Association for Children with Cancer  
Athens, Greece*

## Announcements

### **27 - 29 May 2004**

#### **International Meeting in Valencia**

Organized by ASPANION

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

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

ASPANION

Plaza Pablo Picasso, 9-3ºD

46015 Valencia

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

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

### **25 - 28 August 2004**

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

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

Hosted by the International Psychology Society

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

### **16 - 19 September 2004**

#### **ICCCPO General Assembly, Oslo, Norway**

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

For details contact:

[mc.naafs@vokk.nl](mailto:mc.naafs@vokk.nl)

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



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

For more information please contact:

Congrex Holland BV

P.O. Box 302

1000 Amsterdam,

The Netherlands

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

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



Marina Novitskaya

**Art and handicrafts by the hands of children with cancer:**

## Art therapy and real prospects for the future.



We Ukrainian parents and volunteers can do so little for our children with cancer. In our country, suffering from crisis, almost all of our activity is focused on searching for financial support to give the child everything necessary for its treatment.

Our rehabilitation and education programs are, so to speak, still in the embryo stage. But we never forget that the emotional condition of the child is one of the most important components of the treatment.

The doctors who treat our children constantly remind us of that. They prescribe the small patients "vitamin J" (joy). The doctors allow actors and clowns to attend our department. Sometimes the clown is even allowed to visit the sterile box or the intensive therapy ward.

When the child with cancer is admitted to the hospital, the first thing the anxious and terrified parents think of is to get the child busy with pencils, paints and handicrafts—any kind of creative art.

Such a decision has a lot of advantages from the parents' point of view:

- this kind of activity is usual practice in all institutions involved in working with children;
- any adult is able to make something of that kind and teach the child as well;
- this activity does not demand much expenditure;
- at least the child can do that alone without anybody's help, as he or she might with reading.

This is the way most parents think. That's why each child admitted into hospital has a notebook, an album, a pen, pencils and fountain pens amongst his or her things. Sometimes there's a set of colored paper or several colors of beads. The parents can not even imagine how right they are, placing such strong hopes on handicrafts and creative art as a means of support in the disease.

We can divide the whole art-therapy into three STAGES, though the division will be a bit hypothetical. In fact, there is no strict border between the stages and the point at which the child goes from one stage to another is very peculiar to each child. Moreover, not each child goes through all stages as must.

The first stage of creative art activity has the clearest aim: to fill the child's free time, to save him or her from dullness and boredom, to draw away the child's thoughts about death.

Our organization works for the department of oncology, which admits children for treatment from all over Crimea. Crimea is the resort region of the Ukraine. The area of the Crimean peninsula equals the area of Belgium or Albania, and is twice as big as Israel. I give these figures here to show the following situation: the children with oncological diseases spend the greater part of their treatment –and this is from 6 months to a year – in hospital. Most parents live in distant regions of Crimea but even those who reside in the administrative center of Crimea where the hospital is located, have no opportunity to transport the sick child safely to their home or are not able to provide the child with the necessary safe conditions at home, especially after they have received a course of chemotherapy.

When the child has problems in the course of the chemotherapy, he or she has no opportunity to study the school subjects without the help of parent or teacher. Even if child's state of health allows him to study, this is impossible given the hospital conditions. There is no educational center here; the children have no opportunity to obtain correspondence education as well.

During the first weeks at the hospital, it is simply a must to find some activity for their hands. I know this for sure due to my own experience. During the first two months of treatment, my son and I studied thoroughly the whole book of origami, and we could have made thousands of paper cranes, but it was necessary to find more difficult models and levels to draw away the dark thoughts.

A child with cancer undergoes the severest psychological trauma which is caused by a set of factors, and we cannot save the child from the impact of these factors.

- First of all, there is the astonishing information about the disease, which is life threatening.
- Secondly, the separation from the child's relatives and friends for a long period of several months.
- Thirdly, the tough course of treatment with its painful procedures and consequent loss of hair.
- Fourthly, children see the suffering of other patients, and very often learn of their death.

But we can help the sick children make their fears, emotions and hopes visible. It is common knowledge

# Regional Group Reports

that a picture drawn by a child can highlight his or her problems, on the one hand and on the other it can become a method of psychotherapeutic treatment.

This is the great field of research by psychologists and psychotherapists, by the way, which is almost unreal to us: there are no funds to pay specialists of that kind, and there is no volunteer psychologist here up to now.

Nevertheless, a lot of patterns are obvious even at first sight.

A newcomer to the department is never deliberately involved in the work; the process of art-therapy begins when the child watches other children work. But creative art is very contagious; all new artists are attracted by the process, willy-nilly. The child is never bored; there is no time for that.

During the first days or even months, the child can only, as a rule, use one dark color to draw its pictures. These pictures usually show something threatening.

For example, July Donets, a very calm and reserved girl, drew animals with big fangs, claws and drops of blood. But when she was discharged to return home from the hospital, she presented the teacher with a picture of a tiger, no fangs and claws showing, all soft and fluffy like a cat.

The teacher analyzed the pictures of Volodya Stogny, an orphan, and noticed the connection between the attacks of aggressivity and the pictures. When the attack was close, Volodya painted the abstract picture in aggressive bright colors.



The pictures of Elena (Alyonka) Kornilova, age 4, need a separate world. This child had been treated for leukemia for almost all of her short life. She had fallen ill when she was one, and after two years of treatment she had had a relapse. Ten months later, in hospital, Alyonka had a third relapse, which led to her death.

Alyonka's pictures repeated the only motive: horrible black sun, which looked like a jellyfish or wheel, spreading the tentacle-rays towards a small helpless figure (teddy-bear, small ship...) - and a small, but very bright sun, which saves the small figure and takes it aside of the black monster. One of her pictures had the black sun on the sea background at the bottom of the list, and the bright one shining in the sky. The girl captioned the picture with these two lines: "I don't like the black sun, I go for a walk with the red one." The girl gave this comment: "The black sun is a bad one, that's why I've thrown it into the water, let it sink."

There is no black sun in Alyonka's last picture. No images in fountain pen, just color-abstract compositions, fine and delicate aquarelles of calm and harmonious shapes...

A special group is formed with pictures on medical topics. Children usually draw their doctors. There are several such portraits on the walls of the doctor's room, carefully pinned near each doctor's place.

Certainly the teacher directs the creative activity of the children, but with all possible tactfulness and without pressure.

The teacher offers the children the chance to prepare happy pictures for any holiday, showing the child's family on the picture- and of course the child is supplied with the brightest and the most joyful pencils and paints. Once the patients of the department were given the theme: I am back home! The enthusiasm the children showed needs no words! To the current survivor's day, the entire department (children, parents, doctors, and led by the teacher) created a huge poster:

blue sky, a sun, white clouds, flying birds, green grass and blue sea. The artists made this picture, dipping their hands into the paint and stamping their hands on the white paper. All the images were made by their handprints. But unfortunately one of the small artists experienced an allergic reaction to the paint, her hand got all inflamed. That's why the teacher never applied this method of painting again.

But when each child creates something without any help, choosing the topics itself, the pictures or handicrafts turn out to be jolly and festive. They are full of suns, rain-

bows, blooming trees and blossoms, butterflies, all kinds of animals and very often waves of the sea. The names of the pictures speak for themselves: "My dream", "Rainbow", "Spring in Cosmos", "Merry Clown", "Sunrise in Crimea", "We are all going to build a new house". Children with leukemia drawing holidays, they are happy in this life, they are confident that they will overcome this disease.

The personality of the creative art teacher is of great importance through all three stages of art therapy. During the work with children, the teacher not only teaches them art, but also works as a psychologist.

Skilful teachers usually involve different kinds of creative art activities: painting and drawing, embroidery, handicrafts with beads, application, origami and three-dimensional applications. Materials of quite different kinds are used in creative art activities and match perfectly.



The staff list in the onco-hematological department includes a position for a teacher. For five years, Olga Pavlyuchenko worked with our children. The results of her efforts: our children's artwork has been successfully

shown at various exhibitions, the high quality of the pictures and their expressiveness. She had a great task – to teach the children to overcome different crisis conditions and to obtain inside support with the help of creative art. Olga Pavlyuchenko has kindly granted many important observations and given a factual material of this report. Unfortunately, the state of her health does not allow her to work at the department any longer, but we strongly appreciate her contribution to the psychological health and education of our children.

The second stage of art therapy begins when the child needs something more than just drawing and painting, splashing out his or her emotions, moods and problems. The child feels that it is not enough for him that his works are carefully kept by his teacher or his parents and doctors. The child feels it boring to compare his works with the works of other sick children.

The second stage of art therapy begins when the child with onco-disease wants to compare his creations with the works of healthy children.

It is critical that an adult should be with the child at that moment – a parent, social worker, teacher, or volunteer – a person who can organize the event.

The first stage of art therapy has solved the problem of supporting the spiritual side of the child; it has given the child a support in coexistence with the serious disease and lethal danger. But the works made in the hospital fulfill one more aim – to become the sick child's ambassador to the normal world that surrounds their hospital, to let the children's works show the people and the world the reflection of their souls.

And now, from that moment, emotional therapy takes on the features of rehabilitation. Rehabilitation is included and aimed not only at supporting the spirit at this moment in time, but also in the future.

- First, a child, whose works take part in competitions and exhibitions, gets used to the thought that his or her life is still usual, and that it is normal that it lasts nevertheless. It is twice as good if the competition or exhibition takes place in the kindergarten or school which the child attended before the disease. In this case the child becomes confident that he or she is still taking part in the school life as well as the other

healthy children do. Usually there is no such competition, the child simply exchanges pictures with his former classmates, keeping the communication with them from above the hospital walls, and receiving his or her classmates' support.

- Second, the emotional charge of that work is so high that usually they take the first place awards or get the largest number of appreciation – the spectators' love award. Three years in a row, the works of the onco-hematology department patients obtained the Grand Prize of the Festival of Disabled Children's Art. In 2001 all three prizes of laureates were awarded to our children. These are the winners: Misha Norenko (ALL,14), Masha Galaburda (ALL,11), Denis Alexeev (AML,14), Olya Baraovskaya (ALL,13), and Volodya Rodionov (ALL,10).

So, the child's self-esteem grows a lot, because he realizes that he or she is not only worse than other children, but has in some aspects become much stronger and better.

That's why we usually try to give the child some material evidence of his or her victory or even participation in the competition – a diploma, a prize or photos from the exhibition.

- Third, the quality of the children's artwork is very high, so it is possible to organize auctions like exhibitions or exhibitions with charitable aims. Exhibitions of that kind are regularly held in the administrative center of Crimea, Simferopol. There were some exhibitions in the capitol of the Ukraine, Kiev, and abroad – in the Netherlands and in the USA as well. Now we are planning to organize such exhibitions in Canada and Russia. All the money obtained at these exhibitions is spent on the purchase of new material for art and handicrafts activity, but the main part of the money is spent on medication for some individual cases or for the whole department. Children become conscious that their works are not only high in value, but can also bring real money and be a financial support for their parents. These thoughts give the children the possibility to be proud of themselves and make them seek new expressive means and fresh ideas and to fly higher and higher.

Now the third stage begins – creative art is not only emotional therapy, not only the rehabilitation, but real, steady hope – not hope, but confidence! That this real, special child with the diagnosis of "cancer" has a real future – a future as a valuable, even more useful member of society. In aspiring to new achievements, mastering their creative talents, in search of new artistic decisions, our children acquire the skills of their future professions. The recovery means not only the clinical state, but also returning to the previous style of life.

# Regional Group Reports

Unfortunately, in our country we see - especially from the side of the state - strong disregard and neglect of sick and disabled people. In such circumstances, our children seem to have very low status. But we observe quite the opposite situation when the children return home: their status increases. Such children become popular and take the leading place in different child communities. They continue to take part in competitions and continue to win them; and consequently they start to teach other children not only their skills in creative art, but their new knowledge about real values in life, which they have learned from their own experience.

During the treatment, our children acquire enough different skills to continue their world at home, as well as to enrich their knowledge. They become confident in themselves and their powers, and continue to help their parents, producing creative art work for sale.

Volodya Rodionov (now 12) makes competitions with sea shells and pebbles, makes applications and embroidery.

Masha Demchuk (12, now undergoing treatment)-creates wonderful bead bouquets and compositions with the help of her mother.

Olga Bavarovskaya (15)- together with her mother does embroidery; almost all of the doctors have her embroidery compositions. Unfortunately, Olga has had

a relapse and has been preparing for a bone-marrow transfusion in Kiev.

We need volunteers - men of art, we need them badly. We need people who can constantly and professionally teach our children creative art. We want our children to work as the children in Moscow regional hospital do, where the department of onco-hematology and transplantation of kidneys is supervised by the volunteer group, organized by Reverend Alexander Men.

If something non-material is invested, the skills and kindness of the teacher or the volunteer for example, the children can pay back the investment many times over.

Joy, admiration from the world, hope - we can see everything in the work of our children! Our children, who are considered by many people as incurably ill, can give us such positive energy that we feel able to make our gloomy world bright, taking their emotions as paints.

They usually bring their creative art work as a present to their doctors. We write poems and songs as well, and sometimes even books...

*Marina Novitskaya  
Co-coordinator of raising awareness activity  
Mercy Mission "Overcoming", Ukraine  
This report was presented  
at the recent ICCCPO meeting at Barretstown (2003)*



**The Chemo-Kasper booklet is available in many languages. Visit our website to find your language.**

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

# Our trip to Stockholm

From November 4th to 6th, eight people from our organization traveled to Finland and Sweden. For the children that was a big adventure: a trip by car from St. Petersburg to Helsinki and then by sea from Helsinki to Stockholm. Everyone was on the ferry for the first time. The children studied the 11 floors of the ferry, bought souvenirs in the shops, admired the view

from the deck. Stockholm has surprised all of us by its beauty and singularity. We walked around the city center. The children took photos of the most interesting places. We had time to visit the museum of Astrid Lindgren and the Skanska Muset.

We want to say many thanks to the organization Langinkosken seurakunta and personally to Pentti Holli for the help and attention!

*Olga Semenova  
Co-ordinator  
NGO "Children and parents against cancer"  
Saint-Petersburg, Russia*



We crossed the Baltic Sea. Our ferry-boat had 11 floors! There were shops, playrooms for children's games, machine cabins, plenty of everything. We arrived at Stockholm the next morning and walked to the center of the city, to the King's Palace. To be frank, we didn't see the King and the Queen, but we saw the royal guard - royal guardsmen. Then we strolled around the streets of the Old City and went to visit the museum of Astrid Lindgren. There were so many interesting things on display, though the museum was rather small. After we had seen one half of the museum, we came to a train and went aboard. When the train started moving we heard some sounds in the corners of our car. We looked up and saw little figures, hiding up there, talking about something. They were from one of the fairytales of Lindgren. So we watched and enjoyed several fairytales of this Swedish writer: Karlson, Emil from Leneberge, etc. It was cool!

Then we returned back to our ferry-boat, crossing the Old City again. We returned back home by the same way. When we were back home it was November 6th. I noticed one interesting thing about time in all those three countries: When it is 20.00 in Russia, it is 19.00 in Finland and it is 18.00 in Sweden. I liked this trip so much.

*Pavel Astashkevitch  
12 years old, Saint-Petersburg, Russia*

## In Karlson's world

Hurrah! I traveled to Sweden, more exactly, to Stockholm. On the 4th of November, early in the morning, all of our group "Children and Parents Against Cancer" went to Finland. Though it took a long time it was not dull at all on the way, because we knew each other. When we arrived at the Church in Finland we drank hot tea and got onto the bus that took us to Helsinki in 2-3 hours. The bus stopped at the sea port, near two enormous ferryboats. One of them was ours. Then we received keys for our cabins. They were not simply keys, but special magnetic cards. Four people slept in each cabin, which had a shower and a toilet.

## Dear friends,

In the spirit of the recent Christmas bliss, a step before New Year's Day, I would like to wish you happiness, good health and success in the coming year.

Talking about nice matters, the presentation of the booklet we translated from the German version was a significant event in the oncology ward of the Children's hospital in Skopje. In the presence of parents, members of medical staff and friends the leader of department, Prof. Muratovska, spoke well of the initiative. She said that through the written word the everyday experiences on the ward can be

made easier. The simple language used for explaining the disease and its treatment makes this book readily acceptable by the parents. The 200 copies of this booklet were given by our parent association to the department of oncology, with the basic aim to make this book available to all parents confronted with the problem of childhood cancer.

With deep hope that our collaboration will go on, I send my best wishes to you.

*Natsha Kotlar-Trajkova  
Skopje, Macedonia*

# Conference for families and patients



Our traditional annual conference dedicated to the problems of cancer children and their families in Sumy region "You are not alone" was held on the 5th of December, 2003.

Among the participants of the conference were cancer children, their parents and relatives, journalists, doctors, nurses, representatives of Sumy local administration - all who are not indifferent to the problem.

The main target of the conference was to push the interests of cancer children and their families to attract the attention of the community to their problems. The participants got a chance to learn more about cancer. The families of the cancer children discovered that they are not alone and there are others who experience some of the same pain, there are people who support their children, give cancer children the chance for life. A lot of words of gratitude were addressed to the sponsor of the project "Children's pain" Austrian Kinder-Krebs-Hilfe - an only organisation which supports this life-asserting programme and made cancer children appropriate treatment accessible.



The atmosphere of the conference was very sincere and emotional. Long-term survivors, very beautiful young boys and girls, talked about their experiences and shared their wisdom with others. The results were amazing: many cancer children and their families became more optimistic and left the conference with the feeling that they are not alone!

*Svetlana Shut  
Charitable fund "Viden".*

**Two interesting websites for survivors:**  
[www.sac-adol.fr.fm](http://www.sac-adol.fr.fm)  
[www.jscforum.net](http://www.jscforum.net)

Regional Group Reports

# Finding a way to help as much as we can

Starting with big greetings from Bosnia and Herzegovina and the Association "The heart for the kids with cancer in FBiH" (Srce za djecu koja boluju od raka u FBiH) we would like to inform you about the forthcoming events here in Bosnia and Herzegovina with regard to the ICCD day 2004. Namely, in cooperation with the Chamber of Economy of FBiH we are preparing a great Fashion show in the Grand Hotel in Sarajevo. At the same time we will have the presentation of our work (we are a very young Association – founded in April 2003 with the help of our "twin association" from Luxemburg – thanks to Marie Marthe Bruck Clees and Francois Schoentgen). We will show our brochures, calendars, greeting cards, etc. and expect a lot of people from the diplomatic core (ambassadors in BiH) will come as well. The representative of BiH, Mr. Paddy Ashdown, supports this event. There will also be entertainment (such as music) and we are expecting to inform the public in Bosnia and Herzegovina about the problems all of us are facing in the fight for the lives of cancer sick children in our country.

You can find more about the association at:  
<http://srcezadjecu.freewebspace.com>

Invited by NURDOR SCG (National parent Association of cancer sick children of Srbija and Montenegro), our delegation will be visiting Belgrade with the following goals:

1. Finding possibilities to increasing the cooperation with the clinics in Sarajevo and Belgrade.
2. Strengthening the already existing cooperation with the Srbija and Montenegro Association.

Please, consider this as the letter of gratitude for becoming a member of ICCCPO at the annual meeting in Dublin and in the same time to show that we are all working to the same end – to find the way to help our little fighters as much as we can. Once upon a time we were kids. We are trying to help them to help us in becoming better people in society.

*Sabahudin Hadzialic  
Member of the Supervision board  
"Srce za djecu koja boluju od raka u FBiH"  
Sarajevo  
Bosnia and Herzegovina*

Leigh A. Woznick and Carol D. Goodheart:

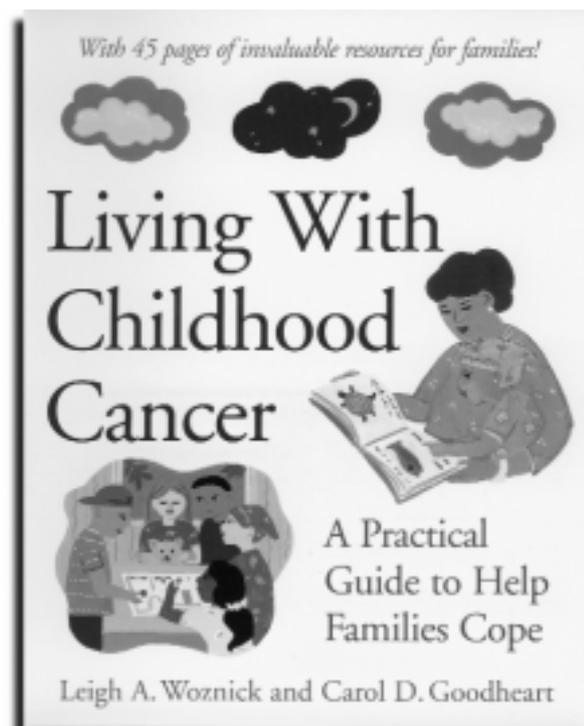
## Living With Childhood Cancer A practical Guide to help Families Cope

Like a natural disaster, the diagnosis that your child has cancer can leave you and your family feeling helpless ...

- How do you explain the disease to the child and his or her siblings?
- How can you communicate your child's needs to hospital staff?
- What are the best ways to reduce the physical side effects and emotional distress of treatment?
- How will you, you child, and the rest of your family cope, and what can you do to help?
- When and where do you find good psychological help for your child or your family?
- How do you manage financial and school issues?
- How can you foster your child's development and self-esteem?

These and more questions are raised and answered in this very comprehensive book, which is a valuable source of information – equipped with a long list of resources (literature as well as websites) – for families as well as care givers.

*Gerlind Bode*



Washington: American Psychological Association, 2002 (ISBN 1-55798-872-2, \$19.95)

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