

ICCCPO



International Confederation of Childhood Cancer Parent Organizations

ICCCPO
Newsletter

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en contacto con
la Secretaria
de ICCCPPO en
Canada.

Some words from the Editors

Before the summer starts we would like to send you this newest edition of our newsletter hoping that many of you are already receiving it as an e-mail attachment. Modern communication makes it easier to reach everywhere on this world within a very short time.

Yet nothing is better than meeting in person - and thus we would like to invite you all to the next ICCCPPO meeting in Luxembourg. It will be a great experience for us all. You will find the preliminary program in this newsletter. For the first time, there will also be an **international meeting of survivors**, who will have their program parallel to the parents meeting with presentations and workshops. A group of cyclists from Germany (all survivors) will arrive at the conference. For information on the survivors meeting contact Simone Mondelaers at simondelaers@mail.be in Belgium.

Also, you will read about the upcoming board elections. And we would like you to think about your nomination.

As SIOP meets in Brisbane (Australia) this year, only those living in the "other" end of the world will be able to attend that meeting. Of course, there will be a full parents program and those interested should sign up to receive it.

You will have realized that the ICCCPPO website is not working quite the way it should be. We hope that it will soon be changed and an active interaction platform again, which should present you a lot of information - including the newsletter to be downloaded. Thus being easily available for many more readers.

We wish you all a wonderful summer and hope see many of you in Luxembourg or Brisbane.

Gerlind Bode, Marianne Naafs and Pia Bonini

and from the board...

We hope that all ICCCPPO-members and associate members did receive copies of the printed version of the Annual Report 1999-2000. This report was printed with the financial assistance of the Lisa Thaxter Trust (UK) and distributed by the Dutch organisation (VOKK).

The Executive Committee met for its mid-year meeting in February in Monza, Italy, where it was most generously hosted by the Comitato Maria Letizia Verga. The meetings took place in the brand new parent house and we visited the ward of the Hospital San Gerardo and exchanged ideas with Professor Giuseppe Masera, who is the chairman of the SIOP Psychosocial Committee.

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Board Elections 2001

At each Annual General Assembly (AGA) elections are held for executive board members. Under the constitution the term of each board member is two years after which they can be re-elected for a further term.

The following board members have served a term of two years and offer themselves for re-election for a further term:

- Marianne Naafs Wilstra (Holland)
- Mark Chesler (USA)
- Christine Wandzura (Canada)
- David Orren(Israel)

Sadie Cutland from South Africa is retiring and not standing for re-election.

Nominations are now been called for Board positions. The nominations should be in writing with a brief background of the nominee and the skills they can offer as a board member. The nominations must reach the ICCCPO Secretariat no later than 30 June 2001 after which time the nominations will be circulated to member countries for consideration before voting at the Annual General Assembly to be held in Luxembourg in September 2001.

As ICCCPO is an international organisation global representation on the board is desirable.

Each board member is a volunteer who is required to fund their own travel costs and accommodation to attend board meetings. Outside board meetings, members volunteer a lot of time in performing their given tasks.

Simon Lala, Convenor - Elections Committee

The Nucleo de Apoio à Crianca com Cancer (NACC)

A parents group in a developing country...

Recife is located in Pernambuco in the Northeast of Brazil, one of the poorest areas of the country. Recife has 2 to 3 million inhabitants, of which approximately 50% are children.

NACC (Circle to Support Children with Cancer) was founded in 1985 by a group of parents, health professionals, and community workers who wanted to start voluntary work to help children with cancer and their families. Their concern was to establish a place where all children and adolescents in need would be able to be sheltered and have psychosocial support while they were being treated. A home away from home was therefore created for these children with cancer. Over 70% of the patients come from rural areas, 15% from Recife itself and the rest from elsewhere.

We have 130 volunteers working in the following areas:

- Administration/Reception
- Occupational Therapy
- Professional Workshops
- Physiotherapy
- Classroom
- Support for external activities

And Employees:

- 1 Driver
- 2 Kitchen Assistants
- 2 Social Workers
- 2 General Services Assistants
- 4 Cooks
- 2 Managers

Arli Pedrosa, Recife, Brazil
E-mail:arli.pedros@cephone.com.br



ABOVE: A group of children helped by NACC.



BELOW: Photos of our new home.

What do parent groups/organizations do... ... and how do they do it?

At the local level,

in specific communities and often linked to specific treatment centers, effective parent groups generate programs that respond to the five major stresses or challenges that children and parents of children with cancer face (Chesler & Eldridge, 2000): informational, practical, social, emotional and existential. As long as children get cancer parents will try to find the resources to aid their children and themselves; in so doing many parents reach out to one another and find, join or create local groups. Group activities differ according to the needs of parents in different locales, and the resources available to them, but in general groups focus on meeting some or all of the five stresses.

In responding to the informational stresses of childhood cancer groups provide parents with information about the disease and its treatments, about psychosocial issues and coping strategies, and about the medical center and staff (e.g., where to find the cafeteria, who to talk with about billing). They also help point families toward available resources in the community, especially with regard to gathering information about financial and insurance issues. They accomplish this through arranging staff presentations, parent panels, discussion groups, newsletters, special guidebooks or handbooks, and family resource libraries.

Group programs directed to the practical stresses try to ease parents' burdens of everyday living, including child-care and financial responsibilities. This is done through financial assistance, lodging for parents who must travel long distances (e.g., Ronald MacDonald Houses), respite care, and information about practical issues such as school programs or funeral arrangements and how to manage at-home chemotherapy. Many groups raise funds to help pay for treatment, purchase wigs, prostheses or in-hospital television service for children and to help pay for travel, parking or extraordinary bills for families. Some groups contribute funds to their local hospital - to improve services for families or to support research programs. These practical issues are especially potent in the less wealthy localities and nations, where basic medical treatment (trained expertise, chemotherapy drugs), post-treatment access to clean water and air, and even funds for travel to clinics are either unavailable or prohibitively expensive for all but the very affluent.

In responding to the social or interpersonal stresses of childhood cancer local groups often support parents who feel isolated and awkward with their prior families and friends and provide them with alternative social networks. They do this through group meetings and discussions, connections with veteran parents who know what they are going through, social and recreational events for the entire family, and home or hospital visits. Some groups also have established summer camping programs for children with cancer, their siblings, and on occasion their entire families. The funding and creation of telephone trees among parents and computer links between hospitalized children and their schoolmates are other examples of efforts to reduce social isolation.

Groups also help people deal with the emotional stress and personal trauma of a child's life-threatening illness, with potentially intense familial conflict and confusion, and with the ups and downs of hope and fear attendant upon treatment. Such programs focus on peer affirmation and co-counseling, "emotional rap" sessions, mutual empathy and sharing of deeply held feelings. Some groups hold special sessions for mothers and fathers separately, for teenage patients or siblings, and for bereaved parents.

In responding to the existential or spiritual stress of this illness groups help people "make sense" of their experience and place it within a framework of belief in a spiritual or secular faith, including issues of religious belief and challenge. They do this through the creation of "narrative communities" wherein parents discuss their experiences and struggles with God and Fate, where they "make sense/meaning" of their past and future situations.

In responding to all these stresses or challenges, and through all these activities, parent groups often work with local medical systems/personnel and community agencies in attempts to assert child and family needs, improve medical/psychosocial/societal care and create change that will benefit them and their children. Above all, the stresses posed by childhood cancer are potentially disempowering; the (re)development of a competent and active sense of oneself, and mobilization of collective energy and engagement with others through such group activities in one way or another help children and their families develop a more empowered outlook.

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Parent Groups continued...

Local parent groups come in many different sizes and shapes. Some are quite large (30-50 active members and several hundred on a mailing list) while others are small (4-6 members). Some create a very formal structure, with by-laws, elected officers and a not-for-profit tax exemption or charitable license (this is especially necessary for those groups that raise substantial funds) while others are quite informal and emphasize personal conversations. Some are long-lasting (in existence for 20 or more years); others vanish in 2-3 years as leaders burn-out or as their children pass beyond this crisis (via either death or cure); still others may lie fallow for a while and rise again when newly energized parents recreate a lay support system. Some groups are run by medical staff members (these are not parent self-help groups although they may be quite useful) while others are governed by parents themselves, perhaps in coalition or collaboration with professionals. Problems of access, transportation and networking make it more likely that medical or cancer association staff members play these key roles in less wealthy areas and nations.

At the national level,

parent organizations may serve both individual parents/families and local groups. They generally coordinate and share information and resources (sometimes including money but usually information, advice and support for leaders) among various local groups via meetings, conferences, newsletters and electronic media. The United States' Candlelighters Childhood Cancer Foundation also operates an information hotline for patient/family concerns, an ombudsperson system for second opinions on medical and legal matters, and a leadership training program for current and future leaders of local parent groups. In many other countries national level organizations provide local groups with services that would be difficult and costly to duplicate at each local site (e.g., funds for group activities or to support individual families' needs, a national newsletter for parents or young people, camps for patients or survivors or siblings, and resources for group leaders). And many national organizations of childhood cancer parent groups sponsor yearly meetings, either of all parents or of group representatives.

In addition, national groups often have access to influential health care policy-makers and the ear of national cancer associations and governmental bodies concerned with cancer policy, health benefits, special educational programs for hospitalized or homebound children, funding of child-

hood cancer research and treatment, environmental regulations that impact cancer, psychosocially sensitive treatment protocols, etc. They often are advocates of change in the delivery of medical and psychosocial care and represent parent concerns and establish liaison with national organizations of oncologic physicians, nurses, social workers and psychologists. Some engage directly in lobbying efforts, both in the legislative arena and with employers and insurance companies, to challenge patterns of discrimination.

There is substantial variety in how and when groups are organized nationally. Of the 31 national childhood cancer parent organizations currently represented in ICCCP, 9 were founded prior to 1985 (8 of these 9 are in wealthy nations, while 7 of the 10 founded after 1995 are in the less wealthy nations). Some were initiated by parents, some by health care professionals, and some by professionals and activist parents working together. All these organizations have national Boards of trustees or overseers, ranging in size from 4-18, and in most cases the national Boards are numerically dominated (50% or more) by parents, with some professional medical staff members, some long-term survivors of childhood cancer, and some members of the general public (e.g. public representatives or major donors).

The size of these national organizations also varies considerably. The United States parents' organization counts some 300 local groups in its family, Canada 45 and Germany 50; but the Japanese organization has 11 local chapters, Sweden 7, and The Republic of South Africa 6. The smallest nations (e.g., Netherlands, Iceland, Israel) often have only 1 group. Similarly, they vary greatly in the amount of funds they raise: associations in many nations, especially those in the less affluent countries, have very minimal funds at best.

These national organizations vary much less in the ways they raise funds and the uses to which they put these funds. A few receive a subsidy from their national governments or cancer associations, but almost all raise funds from public donations and corporate or governmental grants. Several solicit membership fees from parents/families and friends and several others require local groups to contribute to the national organization. Almost every national organization maintains an office and many have at least one paid staff member on site. Funds are expended for educational programs (aimed at the general public, parents of children with cancer, medical and social service staffs), newsletters and meetings that link parents on a personal and/or regional/national basis, support for medical research and facilities and staff, services to

families and children in terms of financial assistance or special housing and travel, and development of local groups.

In some national organizations there are strong lines of accountability between local groups and the national organization. This is true in Canada, Germany and Sweden. On the other hand, in the U.S. there are only informal linkages among local groups and between local groups and the national organization, with the latter operating primarily as an information agency or educational clearinghouse and network of semi-autonomous grassroots groups. The latter form is also common in the less wealthy nations and in nations where a true national organization has not yet emerged. Part of the difference in national-local forms may be related to the history of parent organizing efforts, and the extent to which national organizations emerged from preexisting local groups (bottom-up) or established themselves first and set out to create local groups (top-down). In addition to issues of origins and tightness-looseness, the difference *between* power primarily being located at the national level or the local level means that some national organizations' fortunes rise and fall with the economic and political progress and commitment (or lack thereof) of strong locals. Under these circumstances some local groups have more influence on national programs and operations than do others.

At the international level,

a relatively new organization, the International Confederation of Childhood Cancer Parent Organizations (ICCCPO), was formed in the mid-1990s. ICCCPPO now includes 54 member organizations concerned with childhood cancer representing 43 different countries; 31 of these organizations are national parent groups (others are local groups not yet nationally organized or are organizations not run by parents - Associate Members of ICCCPPO). ICCCPPO has several core goals: **(1) Education** - of parents, educators, physicians, nurses, etc. Parents and parent organizational leaders have areas of special experiential expertise that, when shared, can increase others' knowledge and help direct services more appropriately. **(2) Public awareness** - of the general public with regard to childhood cancer, children's and families' needs, the increased likelihood of survival and normality, and the continuing need for medical and psychosocial checkups and support. **(3) Mobilization and development** - of parents and parent groups at the local and national levels. ICCCPPO seeks to prepare and train parents to create and lead parent groups and so strengthen this worldwide movement. In addition,

parents are encouraged to act as advocates for their children with regard to medical and psychosocial services. **(4) Advocacy** - of adequate medical and psychosocial treatment, of action against social stigmatization and discrimination, and for advance in medical and psychosocial cure rates throughout the world (especially in the less wealthy nations).

ICCCPO implements this agenda through representation and liaison to national and international cancer associations, physician organizations and health agencies (e.g., World Health Organization, International Society of Pediatric Oncologists, European School of Oncology, Monza International School of Pediatric Hematology Oncology), through newsletters and pamphlets distributed to national parent organizations, through visits to member organizations and meetings at which member organizations share their experiences and suggestions, and through a variety of special projects. One of these special projects promotes "twinning" relationships, wherein parent representatives in wealthier nations create personal exchange, training and resource sharing, and ongoing linkages with parent organizations in less wealthy nations.

The member organizations of ICCCPPO share more than a common interest in the struggle with childhood cancer; they also conduct fairly similar programs, encounter generally similar organizational problems, draw heavily on personal and voluntary energy, and are deeply committed to each others' growth and ability to serve children with cancer and their families.

Mark Chesler, Vice President

More from the Board...

We thank the Comitato and especially Pia Bonini and Rosanna Lupieri for their warm welcome. If your organisation wishes to host the Executive Committee for the mid year meeting in 2002, please contact Marianne Naafs or Mark Chesler (EC).

The EC wants to create a list of existing twinning programmes (parent organisation to parent organisation and/or paediatric cancer unit to paediatric cancer unit). If you know of any such twinning or cooperation between a developed and a developing country, please inform us (mc.naafs@vokk.nl).

Marianne Naafs, President

Back to school: School reintegration after childhood cancer

This lecture was presented by two teachers from Holland at the SIOP/ICCCPO meeting 2000 in Amsterdam:

Anna's mother:

We brought our sick child to the hospital and gave her life in the hands of strangers. Hoping they would save our Anna. We felt so helpless. Anna had to go through all these terrible treatments and there was nothing we as parents could do.

Anna got well and after several months we could take our child home again. But she was not our Anna anymore. It was not the physical changes that made her different. No, her whole personality had changed; she cried a lot, she was demanding and performed badly in school. We had a strange child on our hands and nobody could help us. We felt as if we had lost a bit of our daughter to the disease.

With increasing survival rates in childhood cancer, more emphasis has come on improving the quality of life. School functioning is an important aspect of quality of life, because children spend many hours a day in school. And for a child treated for cancer school is of great importance.

During treatment, school tasks are a welcome distraction. School is their grip to everyday life, which they were forced to leave when the diagnosis was made. School has a social function. Each child is one of many, part of the group.

Also, school appeals on the healthy part of the child. And most important, school and school performances give prospects to the future. Therefore, to improve quality of life, it is important to focus on school reintegration of children treated for cancer.

Cancer and its medical treatment have an enormous impact on the child's life, both physically and emotionally. And sometimes children are even faced with cognitive consequences. Children shouldn't be coping with these problems alone. They need help. In the Netherlands, university hospitals more and more recognize the need for school guidance for children after cancer treatment. In the University Medical Centre of Nijmegen (The Netherlands), we are part of a specialized team that focuses on school problems in children with cancer.

Peter, a schoolteacher:

Michael had missed school for some time. I thought he had a bad case of the flu. After three weeks we received the message that Michael had leukemia. This was a complete shock to me. I thought Michael was going to die.

We informed the class. This was difficult because the children had so many questions I could not answer. I told the class it was best not to contact the family right now, because Michael was very ill and the family had a lot on their mind right now.

After two weeks Michael's mother called me. She told me Michael responded very well to his treatment. But she was angry with me, because the school had not showed any compassion. I realized I made a mistake in not communicating with Michael and his parents. I was afraid...

Communication

Good and frequent communication between the three worlds that a child with cancer lives in is a crucial condition for school reintegration: the family, school and hospital.

School reintegration is a process that should start soon after diagnosis. The first step is to make sure the child's school is informed about the diagnosis and gets all information needed. Usually the parents contact the school to inform them. It is very important that parents, school and hospital arrange an agreement on certain practical issues, such as:

- Who is the informant in school?
- What information can be told to the classmates and their parents?
- Can the child attend complete school weeks?
- Is the child permitted to join the gymnastics classes?

In the Netherlands, hospital schoolteachers play an important role in the communication between the three worlds. They have contact with the medical staff, the parents and the teacher of the school of the sick child.

Recently, most hospital schools have put together an information package for schools. This package contains information about the hospital school.

Furthermore, it contains information materials of the Dutch Childhood Cancer Parent Organisation and of our centre: two books: 'A student with cancer... now what?', which is a workbook for schools and the book 'Childhood cancer - chances in education'. This package is a good addition to the information given by the child's parents.

Consequences

With information and good communication the expected school reintegration can be prepared. The school can prepare itself for possible consequences the child might suffer from caused by the disease and treatment. These possible consequences consist of three components, which are inseparably connected: physical, emotional and cognitive. These consequences can be temporary, long term or even chronic. Some consequences are more severe than others. We'd like to go through a few examples.

Physical consequences are dependent on the specific disease, the treatment and possible complications. Common physical consequences are:

- **Reduced resistance:** especially during treatment children are very susceptible to infections. If many school children have the flu, the child treated for cancer is forced to miss school.
- **Motor problems:** caused by e.g. a leg amputation or a neurological problem. The seriousness of the problems varies from not being able to walk to having writing difficulties.
- **Hormone changes:** some children need supplements to substitute certain hormones. As a result they can for instance have problems coping with stress.
- **Fatigue:** this can be temporary, but is also known as a chronic problem.

- These physical consequences have direct impact on school functioning and school performance.

Some physical consequences cause emotional problems, like the loss of hair.

Emotional consequences are more or less found in children with cancer, depending on a lot of factors like age, coping style, family support, etc..

- Many children suffer from relapse anxiety.
- Depending on the physical condition, children have to learn to accept their handicap. This process can take years and can cause new problems in every new life phase.
- In a way children treated for cancer feel different; different from who they were before and different from other children. If they don't feel accepted by their peers, they tend to withdraw from other children.

Marian (17):

Two years ago I was treated for a brain tumor. I had an operation, chemotherapy and radiotherapy. After the treatment I wanted to go back to school as soon as possible, because I didn't want to repeat a whole school year. But it didn't work out the way I planned it. I had trouble concentrating in class. And I was not able to write my notes while listening to the teacher. By Wednesday I had become so tired that I'd rather stayed in bed for a day. In school, the teachers said my motivation was very poor. I started to doubt myself. I lost interest in school and wanted to drop out and look for a job. My whole future seemed to collapse like a house of cards...

A subgroup of children treated for cancer has to deal with cognitive consequences. Children who are particularly at risk to develop these problems are:

- Children treated for a brain tumor. The tumor itself, the high pressure it can cause in the brain, and the intensive treatments are infamous.
- Young children. The younger the child, the more it is at risk for learning disabilities.
- Children treated with cranial irradiation like children with a brain tumor, leukemia and Non Hodgkin lymphoma. Fortunately, this treatment is now less used than twenty years ago. But especially for children with certain brain tumors a better alternative is not yet available, although the radiotherapy itself develops to a more sophisticated method.

The largest group of children we see in our daily work with school problems are children treated for a brain tumor. Learning disabilities are not always apparent or, if they are, often not identified as a consequence of the disease. Sometimes they become apparent years after medical treatment.

Timothy's mother:

At first, we just wanted to conquer the disease. Make sure we wouldn't lose our child. After an operation and chemotherapy,

Timothy needed radiotherapy to destroy the last cancer cells in his brain. The doctor told us that the radiotherapy could cause learning problems in the long term. We realized that conquering the disease was not the end of our struggle. This therapy could effect Timothy's future. But it was either that or no future at all. We had no choice.

After six months, Timothy went back to school. In the beginning everything seemed fine. He enjoyed school. But after a while, he couldn't keep up with his classmates. He had trouble concentrating, forgot many things he learned and was bad-tempered. When he came home from school, he had no energy left to play. All he did was lie down on the couch and watch television. Although he was so tired, he slept poorly. I often had to sit next to his bed for hours. And his friends didn't come over to play anymore.

His schoolteacher didn't understand. She said: "if Timothy is cured from his cancer, I can't treat him any different than his classmates. Maybe you spoil him too much."

These are the most typical cognitive problems:

Attention deficits

Many children have difficulties maintaining their concentration in class and during homework. Instead of overactive behavior, these children tend to gaze at their paper or out of the window. Risk group children also have problems with selective attention. This means that they have difficulty to give priority to one source of information and block other sources. Like Marian, who couldn't write her notes while listening to the teacher.

Memory problems

Memory problems are often found in children. They have great difficulties remembering new information, especially information out of a certain context, like capital cities of the world or multiplication tables. Memory can be divided in several components; there is auditory memory, visual memory, short term memory, long term memory, etc.. In order to help these children it is important to find out which aspect or aspects of the memory is damaged.

Problems in information processing

Older children have to process a lot of information at the same time. They have to study a number of book chapters for one test. The children in the risk group have difficulty finding the core of a subject and discriminate between main and side issues. You can imagine what happens if they write a summary... they rewrite the whole text.

Lower speed of processing

Learning takes more time. If there is not enough time, assignments are unfinished, children make more mistakes and miss instructions. Some children have to tiptoe for years, until their battery is empty.

These cognitive consequences are all components of general intelligence. Therefore it is often said that these children deal with a decline in general intelligence. You can imagine that cognitive problems can cause new emotional problems if they are not recognized. Physical problems can make the situation even worse.

All in all, school reintegration doesn't automatically mean: pick up where you left of.

Problem approach

But then your next question is: 'what can we do about it?'

There is not one right answer to this question. There is not 'a' child with cancer. All children are unique and cope with their own consequences, some minor, some major.

It is important to evaluate each child separately and try to map the child's needs as well as the possibilities of the environment, that is his family and school.

The problems can be approached on several levels:

- Class level
- School level
- Beyond school level

In class

Children can be given extra time to make tasks and tests. It is not the speed that counts, but the result.

Children can be given shorter tasks: not a whole page of math problems, but half a page: quality over quantity.

After verbal group instruction, the teacher can repeat the instruction for the child, possibly supported with visual instruction (with a task card or framework).

A computer can help children with motor problems.

To learn a foreign language, a tape player can be used to help learn the pronunciation. It also enables the child to remember words both auditory and visually.

To help children discriminate between main and side issues, the so-called 'red line' can be given with keywords or a summary of a lesson.

School level

If this help is not sufficient, a remedial teacher can help the child in several individual sessions. Or advice can be asked from an in-school physiotherapist or speech therapist.

Homework coaching can help the older students.

Beyond school level

Sometimes guidance is necessary from outside school. Hospital schoolteachers can give this guidance.

However, since school problems are often very complex, a combination of physical, emotional and cognitive problems, a thorough psychological evaluation is required by an educational specialist or child psychologist.

For special school coaching in The Netherlands there is the possibility to call in long term coaching from special education schools.

But in some cases, the child needs more than a school can offer and special education is necessary.

Finally

In our opinion, it is important that medical specialists recognize the risk for late effects of cancer and the medical treatment on a child's development, including possible school problems. Therefore, hospitals should provide the facilities to give school guidance for children after cancer treatment. We owe that to our children!

**Tanja van Roosmalen
& Claire Assman-Hulsmans**
Orthopedagogical Centre,
University Medical Centre Nijmegen
(The Netherlands)

ANNOUNCEMENTS

ICCCPO MEETING IN LUXEMBOURG, SEPTEMBER 6 - 9, 2001

All members and guests will stay in the Hotel Inter-Continental (12, Rue Jean Engling, L-1466 Luxembourg)

Thursday September 6, 2001

Until 17:00 Arrival of guests and registration (at hotel)

18.00 Opening Ceremony, Reception and Dinner (parents /survivors)

Friday September 7, 2001

Transportation from Hotel to: EU Conference Room at Bâtiment Monnet in Kirchberg (simultaneous translation available)

09:00-10:30 Lectures:

Prof. N. Graf: Wilms-tumor - a curable tumor.

Prof. J. Lemerle: GFAOP - a French/African group of Pediatric Oncology

Prof. G. Tchernia: L'ENVOL and life quality of pediatric oncology patients

10:30-11:00 Coffee Break

11:00-11:30 Lectures:

Prof. Lengfelder: Tchernobyl - a never ending problem

11:30-12:30 Presentations:

by Parent Groups from Chelyabinsk, Armenia, Egypt, Bangladesh

13:00 Lunch Break

14:00-14:45 Presentations:

by Parent Groups from Argentina, Mexico, Finland

14:45-15:15 Coffee Break

15:15-16:00 Lectures:

P. Bonini / G. Thaxter: Sponsor a Child Program

S. Cutland: Goals and limits of parent groups

16:00-17:00 Interactive Board presentation:

Future Perspectives - Where do we go from here? Visions, Ideas.

18:00 Tour Departure -- For tour on the Moselle River and dinner (parents and survivors)

Saturday September 8, 2001 -- (meeting at Hotel)

09:00- 12:30 Workshops:

on topics like: bereavement groups, website and internet-communication, social issues etc.

13:00-14:00 Lunch Break

14:00-15:00 Poster Viewing

15:00 Arrival of cyclists from Germany (parents and survivors)

16:00-17:00 Long Term Survivors - **A Panel Discussion**

17:00 Guided tour of Luxembourg city

20:00 Dinner

Sunday September 9, 2001 -- (Hotel)

9:00-12:00 Annual General Assembly Meeting

12:00 End of conference and departure

Except for Saturday afternoon, there will be parallel sessions for survivors (detailed program to be obtained from Simone Mondelaers at simondelaers@mail.be)

JOINT SIOP/ICCCPO MEETING IN BRISBANE, OCT. 10-13, 2001

Along with this year's SIOP meeting there will be a parent meeting organized by Australian parents and Simon Lala (for more information contact Simon Lala, EC-member)

Spinach and Raisins for Lunch:

A mother & daughter's story of childhood cancer



Excerpts from a presentation given at the ICCCPPO/SIOP meeting in Amsterdam (Oct.5-7, 2000) by Juanne Nancarrow Clarke and Sophie Broere (who is a Dutch long term survivor and read the part of the daughter). It is a mother/daughter dialogue with alternating paragraphs.



It was the summer of 1995. My 17-year-old daughter and I were spending this time in the city together.

Lauren wanted to get a lot of sunshine, relaxation and exercise.

Call it by name: cancer, leukemia, sick, diagnosed.

Things didn't exactly turn out this way. The doctor on duty at the urgent care clinic asked what was wrong with Lauren and she and I explained that she was "really" tired all the time and pale. I said that I wanted him to order a blood test in case she was anemic. He said to me, "But you're pale, too." And I said, "Yes, but I have lots of energy and endurance." Then he said, "oh, okay" and ordered a blood test. Lauren did not have the energy during this test to keep her head off her elbow on the desk. Here she sat in a public office too tired to keep up the appearance of being well.

As if labeled, named,
by speaking incessantly
it might be
overpowered, destroyed
regain my strength.

The afternoon passed. Words,

eventually told Lauren what the doctor had said. Something was seriously wrong. The doctor said I think it is serious. I asked what he meant what could it be? Leukemia or aplastic anemia. He would make an appointment with an hematologist for as soon as possible and call us back to let us know when it would be.

language itself, numb

He called back to say that the bone marrow aspiration was the next day.

For a word does not throw up every day at three, cry as hair clumps in front, believe that being held can save. I still really did not think that it was happening. A word does not cure.

I continued to work at my desk.

(...)

That's not how I remember it. When the doctor called Mom was helping me write out my resume for applying for first-year university scholarships. She was typing what I was dictating because I was too weak to sit up and do it myself. I was lying at her feet and I could hear her voice and see her tears appear. I asked her what was wrong and she told me immediately. We went to our living room and hugged on the couch, crying for a few minutes.

(...)

Lauren and I resolved that the doctor was wrong - she was only anemic.

I was a vegetarian, maybe Grandma was right after all, maybe I wasn't getting enough iron.

He was overreacting, I told myself. He was looking for the worst. So I made Lauren a bowl of spinach for lunch with a bunch of raisins for dessert. She was anemic; these foods were supposed to be iron-rich and we were going to get serious about treating it.

(...)

The bone marrow aspiration was the test we were all waiting for, cloths and trays, slides and tubes, and needles and bigger needles arrived, nurses and lab technicians gathered around the bed, ready to run the bone marrow to the lab for testing. Time stopped. It seemed that everyone had stopped breathing until the doctor laid out her tools and began to explain what was going on. The situation quickly became ritualized.

It hurt it really hurt. I had tears in my eyes, I was wincing.

(...)

The doctor then very quickly assured us that she had the "good" kind of leukemia and that her prognosis for full recovery was 78-82 percent. These were great signs.

All in all, things couldn't have been better under the circumstances.

I heard Lauren's diagnosis. I don't remember feeling: instead I remember planning. I remember thinking, okay that's it, now what do we do? I hadn't eaten for a few days, but I wasn't hungry. I didn't have clothing. I had a full-time teaching position. None of this came to mind. My concern was focused on the immediate tasks that lay ahead.

I guess that is shock.

People always ask me, How did you feel when you heard the news? That Lauren would not live never entered my mind at this point.

A hardness slowly swallows what's left.

I was sure 'she was 100%'. She seemed so healthy, except for the tiredness.

I cry out to stop it, I fear that if I don't something else might and we had a course of action that was to be taken step-by-step.

(...)

But really, we were still in a land of shock. While we were curious about the causes of leukemia and the length and effectiveness of treatment, we were not really yet concerned about the side effects, the long term effects or the after effects. We were not looking ahead in a realistic way. Time was eclipsed yet interminable. Instead we put our trust totally in the doctors, nurses, and hospital. We believed that they knew best, had all the answers and the way to a complete cure.

(...)

What are the causes of leukemia?

We wanted to understand what had happened to lead to this totally unexpected diagnosis. We are as humans, used to taking our worlds, our friendships, our families and bodies for granted. Yet our common sense thinking is causal. We learn to predict our lives through a myriad of smaller and larger signs. Grey clouds often bring rain or snow. Sudden severe sickness disrupts "taken-for-grantedness".

I look back to the past to see if, after all, we might have predicted my illness. I became interested in understanding more about childhood cancers. I wondered how common are they? What are the causes thought to be?

The proverbial question of "why me?" did not seem to enter my mind. For me it was always more about "why not me?"

(...)

And so time passed.

We went to the outpatient clinic at the large hospital for six months. We went to the clinic in town every week for two years. And then we were at the end.

The end of treatment, as long as it was a distance in the future, was anticipated with great delight and hope.

(...)

I am still trying to make sense of what happened. Most of the time it is distant. I have come through cancer and now I am well. But it is not that simple. I forget now that I had cancer. I forget the pain, the fear, the effort, the loneliness. Recently I forgot to call to make an appointment to go to the hospital for my regular blood work. Just like that, what was once my world is no longer. Chemotherapy, its impact on my immune system, and the fear of catching something serious from someone are gone. There are small reminders: my need for naps every day, my more easily bruised body, my thinner hair. But these are minor things. I feel well. I am eating more healthily, exercising regularly, and trying to choose an activity level that does not give me too much stress. Yet, there are times when the enormity of what I have been through, overtakes me. Sometimes I am overcome with tears and grief. I want two years of my life to mean something - I want every day to mean something. Somehow I need to come to a conclusion with this illness, but I think that this conclusion may still be years and learnings away.

(...)

I am back to work full-time. Life is sort of back to normal. I usually do not worry about Lauren's health. If she looks very pale, has the flu, or feels particularly tired, I get alarmed, but I am usually able to put it out of my mind and to trust that she is better. Although I live with uncertainty it is in the midst of optimism.

I have gone through a lot and I am healthy. But, I think, we all go through a lot and we all need to be healthy.

I am amazed at how normal life usually seems now – when we were in the thick of it I couldn't believe in or imagine a future when Lauren's health, her well-being, could ever again be taken for granted. But then, I guess, it isn't—quite.

(...)

And now she is well.

Juane Nancarrow Clarke
Finding Strength: A Mother and Daughter's
Story of Childhood Cancer. Toronto: Oxford University
Press, 1999

NADEZHDA *means Hope*

My name is Irina Proskuryakova. My son was diagnosed with leukaemia at the age of four. He died when he was 16 years old. I felt a strong desire to share my pain, my experiences and lessons I learned.

That strong desire resulted in the founding of a parent organisation in 1992 in the city of Novosibirsk. I became a chairwoman of that organisation and of a guardian counsel as well. The aim was to help families with children who have leukaemia.

In 1996 I had an idea to establish a centre where ill children could have professional medical and psychological help. I was permitted to take an old building and do the reconstruction. Everything was done with the help of our city administration, sponsors and volunteers. The opening of the centre took place on December 14th, 1999. At present I am the director of the Foundation and in December 2000 we celebrated our first anniversary. We called our centre "Nadezhda" which means "Hope".

Nowadays the Novosibirsk City Foundation To Help Children With Oncohematologic Diseases "Nadezhda" is the only public charitable centre of such kind in Russia. It exists thanks to the generosity of our sponsors and some public funds.

Our centre helps those families with cancer sick children who live in Novosibirsk its region as well. Leading specialists of the city examine our children. Moreover separate programs are developed for each child taking into consideration its physical, psychological and intellectual abilities. The children have different school subjects such as Russian, Literature, Maths, Geography, English, Chemistry, etc. In their spare time they play games, sing songs, dance and make excursions around the city. They get four meals a day.

The centre helps not only the children. Their parents can consult a lawyer, a psychologists, our doctors and nurses, etc. And all this is done absolutely free of costs.

We have many plans but the administrative help is very minimal and we are in need of financial support. Nevertheless "Nadezhda" Foundation works and will work, I hope.

Nowadays our children have the dream to attend an international camp and meet children from other countries.

We will do our best to make their dreams become true.

Irina Proskuryakova, Novosibirsk
E-Mail: proskuryakova@mail.ru

MISCELLANEOUS

Making a Mark 2001

Is an exhibition of art by children touched by cancer. All patients and their siblings are invited to send in their art work to be exhibited in various places. For more information contact:
Carol Herron
Arts and Medicine Program
Coordinator
Texas Children's Hospital
Tel. +1 (832) 824-4104

International Childhood Cancer Day

ICCCPO is planning an international Childhood Cancer Day to help raise awareness globally, and to provide parent organizations with a vehicle to fund-raise for their local work. The proposal will be put to parents at the ICCCPO conference in September. If adopted, it is expected ICCCPO will declare the first international day in 2002.

A book report:

Fly with a Miracle

by Sheila Belshaw
(London: Denor Press, 1999)
"A true story of personal courage and medical triumph" is a powerfully written report by the mother of a young man with osteosarcoma. Though Andrew has to be operated and intensively treated he manages to realize his dream and becomes a pilot. The gripping literary style makes this book very interesting and exciting.

Taking care of a dying child

After attending several lectures by parents and professionals during the last ICCCPO meeting in Amsterdam about palliative care for children, I would like to react, very briefly, not judging nor criticizing anyone, but just by giving my opinion and testimony.

I have this need because I'm a little worried that the participating non-European, non-North American parents (who very often take Europe and North America as an example) might think that the only way to prepare a child who's going to die, is to tell the truth, the whole truth and nothing but the truth.

I would like to emphasize, though, that first of all, each case is different and that the sentence from the Australian father Mr. K. Liebke during his lecture about "Palliative care needs of families" says it all: "I don't know if it was right or wrong, but it suited us."

After "recovering" from the tremendous shock that "nothing could be done anymore" for our daughter of seven (2nd relapse ALL) we had to sit down and decide what to do. Me (40years), mother of two, nurse, North-European, living in southern Europe for 16 years, no religion, married to a South-European (42 years), T.V.-director, no religion. Our other daughter was 6 at the time.

We decided not to tell our child that she was going to die. We found the idea too cruel: taking away her hope and make her feel afraid, anguished. We were unable and unwilling to tell her that this was it. I

could not tell her that there's a heaven if I myself don't believe in such a thing. We don't know what it is to be dead! For a child of her age the big fear is to be separated from her mother (and father).

We tried (and I think we succeeded) to continue a normal life as much as possible for her and her sister. And we never stopped planning for things and talking about the future.

Despite the infinite sadness we felt, we had a very good time together, the last 7 weeks. As a nurse I could care for her in terms of medication, morphine catheter, etc. at home in her own surroundings, meeting her friends, sometimes going to school, taking care of her animals, playing with her sister, eating Hamburgers at McDonalds, having her birthday party one day before she died, careless, without any worry, relaxed, and of course sometimes in pain, but for that we had painkillers.

To be able to take care of a terminally ill child at home we have to feel confident, sure and secure and in this field still a lot has to be done. I think this is a right everybody should have; *to die at home with our dearest close to us*. But unfortunately this is still a privilege for a few.

I would like to end in repeating the phrase: "*I don't know if it was right or wrong, but it suited us.*"

Ansfriede Zwaagstra, Portugal

Reduced Fees

We remind you that the yearly fee for ICCCPO membership is \$500 USD. However, groups that do not have sufficient financial resources are permitted to apply to pay reduced fees. A minimum fee of \$50 USD is required to enable a group to vote at the Annual General Assembly (this year in September in Luxembourg).

If you desire to request a reduced fee please write, fax (+734-7636887) or email (mchesler@umich.edu) Mark Chesler, ICCCPO Vice-Chair. Include information on your group's yearly income and budget and a specific statement indicating why your organization cannot pay the full amount. Indicate as well the amount you are willing and able to pay.

Some ICCCPO members may be able to create a "twinning" arrangement whereby a group with adequate financial resources can pay the fee for a group with inadequate resources. Each group must make its own arrangements for such support. And, if one group is paying another group's membership fee on a reduced basis, that still must be requested in writing.

Remember, your membership fees (full or reduced) still are the principal source of income for the International Confederation. We are all dependent on everyone else making a reasonable effort to pay the full amount. Otherwise we will not be able to carry out the programs everyone benefits from.

Mark Chesler, Vice President

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