

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

Notes by the editors and the board

As we came home from a very good meeting in Luxembourg on a new high with a sense of how well we are doing as an organization, we all were called back to a totally different reality: the terror attacks in New York and Washington shocked us all profoundly and leave us with the question: what effect will it have on the world and all our actions?

At this point we all hope that the sense of solidarity expressed all over the world right after the terrible attacks is the same genuine feeling of solidarity which supports all our actions within ICCCP - across cultural and religious boundaries.

The conference in Luxembourg was such an example of solidarity and it was the first international parent meeting that also involved a survivors meeting. Young people, former patients, from many different countries came together for very intense sessions of their own, topped by the arrival of 25 cyclists from Germany. The cyclists are a group of survivors who unite once a year to go on a bicycle tour which takes them through different parts of the country, stopping at all the hospitals along the way which treat children with cancer. It is their way of encouraging those presently in treatment with their appearance - the positive reinforcement they all wish they would have received themselves.



The survivors plan to keep on meeting at a regular basis (in connection with the ICCCP meetings) and have started to establish their own network. They elected an informal board which will do the planning and coordinating:

Anthony Penn (South Africa / UK)
Andreas Würsch (Switzerland)
Simone Mondelaers (Belgium)
Sophie Broere (The Netherlands)
Eva Coenen (The Netherlands)
Paolo de Souza (Luxembourg / Portugal)

They can all be contacted through their respective national parent initiatives and will give us their specific email addresses soon. Pictures of the meeting can be found on from the Swiss website: www.SwissCCS.org (Swiss Childhood Survivors).

The election for the ICCCP board brought only a very minor change: Julian Cutland (already responsible for the website) was elected as board member at large as Sadie stepped down still remaining to be actively involved in ICCCP business. The position of Rogelio Araujo remained open as no nomination was received prior to the meeting. We would like to encourage all those who wish to be involved in ICCCP's business or who know of suitable candidates to think about the nomination in due time.

Plans for the meeting in Porto have already started. We hope to see many of you there as well as new faces from all over the world.

Gerlind Bode, Pia Bonini, Marianne Naafs-Wilstra

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New address for the ICCCPO Secretariat

For several years Candlelighters Canada (CCCFC) has hosted the ICCCPO secretariat and they did this at no costs. Candlelighters' support and efficient work has been a great support for ICCCPO during a period of relatively rapid growth. We especially thank Janet Evans for the kind and effective co-operation.

At this moment Candlelighters Canada is in the midst of a huge reorganisation and no longer able to host the secretariat at no cost.

The financial position of ICCCPO is not stable enough to have a paid secretariat. Therefore the General Assembly has decided to divide the various tasks among several members. All "tasks" will be portable – ICCCPO is a "virtual organisation". By taking the loads from the shoulders of one organisation, we hope to guarantee continuation and to diminish the risks.

The physical address of the ICCCPO Secretariat has moved to the Netherlands:

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The financial administration is with Simon Lala, New Zealand.

The newsletter will be in the hands of the German Leukemia Foundation

The website will be managed by Julian Cutland, South Africa.

The resource centre will be hosted by Kids Cancer Care Alberta.

New members

At the AGA the following organisations were adapted as new members:

- Kids Cancer Care Foundation of Alberta, Canada – associate member
- L'Envol, France – associate member
- Fundacion Natali Dafne Flexer – Buenos Aires, Argentina – associate member.
- CLIC (Cancer and Leukemia in Children) – United Kingdom – associate member

International Childhood Cancer Day

At the Luxembourg Conference (Sept. 7-9, 2001), ICCCPO declared the first International Childhood Cancer Day (ICCD). The purpose of the day is to raise awareness of childhood cancer and help ICCCPO member organisations raise funds for their work within their own countries.

The ICCD will take place on 15th January in 2002, although we expect some members will organise events over a period of weeks around 15th January.

ICCCPO encourage all members to take part in some way – the more we all take part, the more our voice will be heard, and our needs understood and addressed. To help you, ICCCPO will be sending out a briefing pack so that you can make the most of the event. The pack will include:

- Lapel stickers with the ICCD logo to help basic fund-raising
- The ICCD logo so that you can create your own material
- A media briefing pack to give hints on how to raise awareness
- A fund-raising checklist with ideas on fund-raising events

Sponsoring children with cancer in developing countries

At the conference there was a presentation about how parents and professionals from developed countries can work together to support children with cancer in developing countries.

We heard about how professionals in Italy have helped to establish centralised childhood cancer treatment in Nicaragua. Instead of treatment dissipated in general hospitals, it becomes specialised. This makes support by external professionals easier to provide, and raises survival rates because treatment is dedicated to cancer.

The difficulty then arises that families have to travel further to get to the specialist centre. This is where the parent organisations in developed countries can help. By providing sponsoring, families can then bring their children to the specialist centre.

ICCCPO have set as goal to work with SIOF to develop programs like this in other countries. Discussions are already underway with SIOF in Europe where we have to establish a program between two European countries in the coming year.

ICCCPO Business Plan 2002

ICCCPO recognizes that its members have collective but differing needs. All members are seeking information, emotional and social support. But the priorities of members differ depending on the outcome of the disease. In developing countries, we need to see improved diagnosis and better access to existing treatments. In developing countries where most children now survive cancer, we need improvement in survivor support and programs to help reintegration into society.

The business plan for 2002 has set goals that will put effort into supporting this wide range of needs, and to help ensure that the activities of ICCPO are inclusive. The main goals for 2002 are:

- The International Childhood Cancer Day – 15th January 2002
- Early Warning Guidelines – improving awareness of cancer signs
- Sponsoring children with cancer – a twinning program in Europe
- Supporting the development of an International Survivors network

- Setting up a Developing Countries committee (parent version of PODC)
- Working with SIOF on Guidelines for Care, psychosocial committees, and developing – countries committee (PODC)
- Increasing membership.

Developing a group of SURVIVOR ADVOCATES

ICCCPO is planning to submit a proposal to the European Committee.

Many survivors of childhood cancer represent a unique resource, a cadre of potential "experts" on the ways in which young people can cope with cancer, on how parents can best respond, on what schools and community agencies can do to help these young people, on how medical staffs can better serve this population, and on the need for healthy lifestyles among survivors. When appropriately trained, these young people can participate actively in educational campaigns designed to help ease the psychological pain of children and families in treatment. They also can reduce "at risk" behaviors of young people surviving cancer (e.g., smoking, sun overexposure, dietary excess, sexual risk-taking) and promote their healthy lifestyles, thus potentially helping to prevent second cancers in this population. And they can help educate the general public about the "psychosocial normality" of most children with cancer, the special needs some of them have, and how everyone might best respond to them.

Thus, ICCPO and its participating national organizations plan a threefold pilot program to create and utilize a group of sophisticated CANCER ADVOCATES. We will:

1. Gather information of the service needs of childhood cancer survivors and on the existence in different EU nations of programs designed and operating to meet these needs.
2. Train a group of survivors of childhood cancer in the age range of 18-25 to be peer-counselors and health advocates to young people in treatment for cancer and for other survivors of childhood cancer.
3. Further prepare this group of survivors to work with schools, medical clinics, community agencies and cancer charities to be public spokespersons and advocates for the best possible care for children with cancer.

European groups, interested in this programme can contact Pia Bonini pierangelo.bonini@galactica.it or Gerlind Bode dlfhbonn@t-online.de

Presentation at the 8th ICCCPO Meeting in Luxembourg, September 6-9, 2001

L'Envol, twelve days to alleviate the burden of disease and treatment



During the last decades remarkable achievements have transformed the outcome of children's cancer and leukemia. However, history has taught us that from every step of medical progress new problems would emerge.

While the survival rate improved and as the word «cure» could at last be pronounced, we had to face the physical consequences of our treatments, such as secondary malignancies, growth impairment, sterility. For years we have balanced the risks and benefits of our protocols, in order to decrease sequelae and side effects, while steadily improving the number of children

effectively cured. Considerable progress has been achieved in this field, but the fight is far from over.

We have learnt that the price a child has to pay for being cured can be extremely high. While we were facing the problems of physical impairment in survivors new facts emerged: psychological consequences of fear, of aggressive treatments, and of logical but detrimental long-term family overprotection could deeply hamper self accomplishment and future social integration.

Nevertheless, it became obvious that a child who had been or was affected by a life-threatening or a long-term disease had tremendous abilities to overcome distressing conditions and could build his life and reach self achievement, as long as he could find the proper help in proper time.

Finally, the concepts of resilience and quality of life were reached.

During the course of the disease the sick child meets 3 kinds of partners: parents, school mates, medical and nursing staff. With either of them, communication and verbalization of distressful thoughts appear to be uneasy:

- With parents because anguish and love can on both side impair free expression (everybody trying to protect everybody).
- With schoolmates, when school can be attended, because the sick child has been through a unique experience which blunts connivance.
- With the medical and nursing staff because hospital stays are a time for questioning and fear about the outcome of the disease, the results of X-rays and laboratory tests, and the future treatment modalities.

There is an obvious need for communication with other adults, for peer support and for maturation through new interest and activities.

L'Envol is a non-profit association which provides a medically supported recreation center assigned to welcome children and adolescents suffering from malignant or chronic diseases for a 12-day stay. It opened five years ago. L'Envol aims at reconciling children with life and at restoring strength and eagerness to fight against their disease or the scars of the disease.

Announcements

Fifth Continental SIOP Meeting in Africa

Date: April 14-17, 2002

Venue: Hotel Président, Yamassoukrou, Côte d'Ivoire

Information:

Mokhtar El Harras (Exec. Comm.)

34th SIOP Congress and ICCCPO Conference

Date: September 18-21, 2002

Venue: Porto, Portugal

Information: Christine Wandzura (Exec. Comm.)

2nd SIOP-Asia Conference – with parent meeting

Date: November 22-24, 2002

Venue: New Delhi, India

Information: Simon Lala (Exec. Comm.)

The final goal is not to forget the disease but to integrate this inescapable experience in the kinetics of revival.

In France, the project has been initiated by Henri Tezenas du Montcel and Daniel Alagille. L'Envol has been and is being supported by Paul Newman, after the success, in the USA, of the first center built in Connecticut named "The Hole in the Wall Gang Camp", which opened in 1988, and, subsequently of four other centers in the US and one in Ireland.

The center, 80 kms south of Paris, is settled in a one-century-old castle surrounded by 80 acres of woods. Surrounded by a secure and stimulating environment, each child is invited to become an actor who chooses among a wide variety of leisure activities, those through which he will, hopefully, gradually face himself, its illness and the outside world with a new perspective.

The steps leading to L'Envol are the followings: most of the time, L'Envol is known through previous attendants, family associations, nurses, social workers, or pediatricians. From this information, the referring pediatrician in charge of an affected child, fills an application which is submitted for agreement both to the French Social Security and to the medical staff at L'Envol. The Social Security partly supports the cost of the stay, which brings a different dimension to the institution, when compared to similar institutions with only private funding.

For the past five years, L'Envol has welcomed 2061 children,(2229 stays, as some children came several times), age ranging from 7 to 17 years, during 12-day stays from March to September.

There is a high proportion of boys, due in part to a high number of hemophiliacs.

Most of the children come from France. However, we hope to reach in the forthcoming years a higher proportion of children from other European countries: we welcomed this year 34 children from Luxembourg, Spain, Belgium and Greece. Mixing languages and cultures appears to be beneficial.

Regarding the nature of the diseases, during this year's sessions, oncology (leukemias, lymphomas, solid tumors) accounted for about 30% of the

recruitment, sickle cell anemia for about 12%, AIDS and constitutional immune deficiencies for 9 %, hemophilia for 5%. The coexistence of acquired or chronic constitutional disease appears to be beneficial, each child admiring the way other children cope with a different disease.



During the spring period as the attendants are less numerous than during the summer vacation we are able to take in charge more severely disabled children.

Health security relies upon the medical staff consisting of one full time and one part time pediatricians, a team of nurses with a supervisor, a chemist and a secretary assistance. The medical staff collaborates with a nearby hospital (pediatric department, laboratory tests and X-rays), when needed. Connections with colleagues of the hospitals who sent the children to the center are often required.

Once the medical security is established what is the scenario? The medical staff works in constant relationship with counselors in order to define individually which activities are appropriate according to the children's condition.

To provide security, one adult (counselor or volunteer) supervises two children. The children are divided into age matched subgroups of 8-10 children who share bedrooms and are under the daily

responsibility of 2 counselors and 2 volunteers (the volunteers work only for 12 days, while the counselors are hired for several months).

Most of the children arrive with their parents and the first challenge is to raise quickly their interest in order to alleviate the distress of the family separation. During the first 3 days children have a first glimpse to most of the activities in order to be able to achieve personal choices for the following days.

Painting or carving, music, theater play, swimming in the heated pool, boating or fishing in the pond, nature watching or gardening, horse riding, taking care of animals, video making are the main activities.

As L'Envol is derived from a long history with the French airforce two highlights of the stay are the hot air balloon and a short flight in a small plane with the staff of «aviation sans frontière».

One of the main concerns of the stay is the preparation of evening parties, dances, songs and theater plays for which the children create the scenario themselves.

All these activities have mandatory common features:

- There is no competition and hence no winner and no loser
- Time for communication between children and between children and adults is preserved and places for private conversations are readily organized
- There are 3 periods during the stay : Initiation, Free blooming, Deceleration for landing before departure with the hope of long time benefit.

The aim is to constantly increase autonomy, self-esteem, and confidence through games and communications. We definitely want this aim to be more ambitious than an occupational sojourn with a lot of fun.

We want children to feel they have improved their abilities and realize they have done things they could not believe they would be able to do some days before. Therefore, activities are in accordance with their own pace.

We emphasize that the aim of L'Envol is to realize a continuous fit between activities and everyday health and mood in a tailored individual schedule in order to fit each child's personality and physical condition.

Once back home we want a child to show videos and pictures to his parents and to say: "look, now I can do it". Every child goes back home with a videotape illustrating what he has experienced. Hopefully at that time he has improved his self

regard and can in turn help his parents to evolve from overprotection to a more open-minded unstressed partnership.

Assessing objectively the short and long term benefits of a stay in L'Envol is not easy. However I would like to emphasize some remarks from several interviews who have been found to be recurrent.

"I first thought I would not be able to do much. I had trouble with my back. I saw children with conditions worse than mine, and realized I did not deserve so much compassion. I participated in all activities, including horse riding". Sophie, 15y, France.

"My parents overprotect me and stick to me like glue. At L'Envol, I was proud to have achieved so many activities. I felt free and confident". Charles, 16y, Luxembourg.

"I was somber and gloomy. I met children more disabled than I am. And they laughed. Now I love laughing. Children and counselors have transformed my feelings". Victor, 14y, Spain.

"After a long dark period, I met you. You led hope to be restored in my heart. Far away you brushed the shadows... ..I will one day walk in your steps..." Aline, 15y, France.

There are several beneficial side effects during or after a stay at L'Envol:

- The parents: feeling non-guilty and being confident in the medical security, can either take time for themselves - a break which is often necessary after months or years of struggle and distress - or take more care of the siblings who are often left aside and can turn out to be jealous or sad.

"Quentin has attended a summer camp like his elder brother. An important point for him. This allowed us to share some days with our other son who eagerly needed it..." Quentin's (12 y.) parents (France).

- For the volunteers: taking care intensively of severely ill children leads to questions about life and death and can accelerate psychological maturation and help to better organize the hierarchy of individual problems.

"It took me several weeks to overcome my stay at L'ENVOL. Tiredness of course but most of all deep emotion and great joy. Children were exceptional : both so fragile and so strong" (Laure, volunteer, 22 years).

Finally, we now feel we have acquired a knowledge which can be applied to a great variety of distressed children. Our aim is to widen our actions in time and space, that is to welcome

children 8 to 10 months per year, including school periods. This aim needs other methods such as mixing school and leisure, organizing short stays for families and family associations, welcoming siblings and patients during week-ends. In space with more children originating from other European countries and hopefully from Eastern Europe or Southern countries, as soon as we can find the funding.

Our ambition is, by sharing experiences between all categories of involved adults, to reach a better understanding of the way to help children: through respect, discretion, and admiration for the way they accomplish the tremendous task of coping with a distressing situation.

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(R. Saadoun, S Ulsjacz, C. Fichet, C. Pingot, M. Lebech).

Living Beyond the Sword of Damocles: Surviving Childhood Cancer

As a result of advances in diagnostic and treatment technologies and the coordination of childhood cancer treatment protocols via clinical trials, 3 of every 4 children and adolescents diagnosed and treated for cancer will attain complete remission and cure. In an era in which good health is not just the absence of disease but also the presence of psychological and social well-being, have these advances in pediatric oncology resulted in what van Eys called a "truly cured child?" Furthermore, what about the family? Do we really understand the full impact of having a child, brother or sister diagnosed and treated for cancer? Answers to these questions have the potential to define comprehensive and quality cancer care for this population in that the delivery of health care services must attend to the immediate and long-term health and well-being of childhood cancer survivors and their families.

In their seminal studies of the psychological and social implications of surviving childhood cancer, Gerald Koocher and John O'Malley suggested that a metaphorical sword hangs by a single horsehair over the head of cancer survivors and shadows their lives ever after. This image suggests that a childhood cancer survivor's life is forever tinged by the uncertainty of cancer reoccurring and perhaps again creating upheaval in the survivor's life. Since Koocher and O'Malley's work in the early 1980s, other studies of childhood cancer survivors have identified subsets of survivors who experience psychological and social difficulties years beyond the completion of therapy. Symptoms of post-traumatic stress, diminished self-esteem and body image, employment discrimination, difficulties obtaining health insurance, and limits on educational and employment opportunities due to treatment-induced cognitive deficits all have been identified in studies of childhood cancer survivors.



Panel discussion of survivors at Luxembourg meeting

In contrast to studies and methodologies identifying pathological and problematic aspects of the childhood cancer survivor experience, other investigations indicate that life after cancer is not necessarily all negative. Recent studies suggest that for the most part childhood cancer survivors are psychologically well and in some cases more healthy, in psychosocial terms, than healthy controls and same aged peers without a cancer history. Indeed, existing studies document the extent to which survivors state that overcoming cancer has resulted in positive changes, deep personal growth and an enhanced outlook on life. Although some investigators dismiss these positive attributions to having had cancer as "denial" or "repression," there exists no empirical evidence to support those assertions. To the contrary, many survivors have been very clear about feeling more mature than their peers, as having improved relationships with family and friends, and as having a more clear focus and direction in life.



Survivors from many countries meet in Luxembourg

While the overall picture of childhood cancer survivors may appear ambiguous or contradictory, what is likely is that all these study findings are true to some extent, that survivors can and do experience both negative and positive outcomes. A reasonable summary argues that (1) some survivors of childhood cancer have managed to grow in positive ways as a result of their cancer experience, (2) most probably are relatively normal in psychosocial terms and on most psychosocial measures, and (3) an important minority experiences on-going psychological and/or social adjustment problems. Moreover, all survivors, even those apparently doing quite well, continue to be concerned about the physical, psychological and social quality of their current and future lives.

Indeed, the childhood cancer survivor experience has two faces: one of celebration and hope; the other of uncertainty and fear. Given the potentials for both positive and negative outcomes associated with having had cancer, pediatric cancer patients and their families need on-going supportive care that not only aims to prevent negative sequelae and health risk behaviors but also promotes positive outcomes and disease prevention practices. Responding to these needs requires a better understanding of the factors that increase the risk for negative sequelae in some survivors and promote positive outcomes and behaviors in others.

And what about the family? What about parents and siblings? While most resilient young survivors move on and do not dwell on worries or concerns and perhaps even create personal growth and motivation out of the experience, parents tend to worry for years after. Less is known about siblings, and given their exposure to the same domestic unrest experienced by other family members during treatment, the possibility of long-term psychological and social impact exists. A health care system and research industry that only

focuses on an "identified patient" will miss the emotional fall-out, psychosocial needs and potentials for personal growth expressed by other family members.

In 1998, the American Cancer Society Task Force on Children and Cancer reported that "(T)he progress achieved in attaining 80% survival among children and adolescents and young adults with cancer can be justified only if their physical, emotional, and social quality of life also are protected." Thus, it is incumbent upon the providers of medical and psychosocial care to conceive of childhood cancer as more than just a disease that begins with diagnosis and ends when the treatment protocol ends. Instead, cancer initiates a life-long trajectory of survival (regardless of the length of that survival) having both positive and negative long-term implications for quality of life. Furthermore, since childhood cancer impacts families, the health and well-being of the childhood cancer survivor population is inextricably linked to the health and well-being of their own parents and siblings. Thus, support programs that focus on families are very important. Today's long-term survivor clinics, cancer survivor day celebrations, oncology camps, family retreats, and community-based parent self-help organizations (like those affiliated with the Candlelighters Childhood Cancer Foundation) have become invaluable sources of support to pediatric oncology families throughout an entire span of survivorship – from diagnosis, through treatment, and beyond.

Twenty years ago, Koocher and O'Malley's Sword of Damocles study provided us with entrée into the world of childhood cancer survivors and emphasized an uncertainty about the future that accompanies survival. Recent research, however, indicates that survivors and their families do not wait passively for an ominous sword to come crashing down and shatter their lives. Instead, they adapt to extraordinary life changes and in most cases embrace their futures. As investigators, we can learn from those survivors who have come to wield the Sword of Damocles for their own personal growth. Our charge is to understand how these young people and their families survive, and then to assist in the development and testing of interventions that promote their quality for life!

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Quality of life for children with cancer

Treatment for childhood cancer is long and aggressive. It can even happen sometimes that children feel quite well before they were diagnosed, but much worse after they undergo diagnostic tests and start chemotherapy. During treatment, they can feel rotten, their appearance changes and they have to cope with frequent hospital trips. It is no wonder that parents and doctors sometimes question how far the child's quality of life (QOL) is affected by the whole process. Furthermore, how long will these problems last for? And importantly, can anything be done to improve the child's QOL despite treatment?

The Child and Family Research Group, funded by the Cancer Research Campaign, has been researching these questions for a number of years. We think that asking the children themselves about these things is much more important than talking to doctors or parents – after all, it is the children that are going through the treatment. This has resulted, we feel, in a better understanding of children's views about the effects of treatment on their QOL. So for example, we have found that few children mind very much about losing their hair. They are more likely to be upset about putting on



Luxembourg: Survivors group photo

weight, and they are much more upset about finger-pricks than any other diagnostic procedure. Perhaps these results are not surprising to you. To a large extent, children say that their QOL is also compromised by the way family and friends behave towards them. In particular, they hate to feel that people are talking about them behind their backs. The way school friends react is very important, and can make a huge difference to whether or not children cope with treatment.

As everyone is now convinced that the child's QOL is very important, there have been attempts to measure it precisely. Of course, it is much more difficult to measure something like QOL compared with height or blood pressure! One of the biggest problems is that QOL means something different to almost everyone. For some children, the fact that they can't go swimming because they have a line



fitted is a major impact on their QOL; for other children it is no problem at all—they never did like swimming!

There are now a number of QOL measures that have been published and it is not the purpose of this article to review them. More important is to consider whether or not they may be helpful in any way for the children.

First, a potentially important role is in comparing different treatment programmes or clinical trials. When children are newly diagnosed, parents are very often asked if they agree for their child to be recruited on to a clinical trial. These trials are evaluated first in terms of whether there are differences in physical health between children undergoing different treatments, but increasingly also in terms of any differences in QOL. So ultimately the measurement of QOL should make life better for children.

Second, QOL measures are useful if we want to assess the value of an intervention. We know that return to school after diagnosis can be difficult, and therefore attempts have been made to facilitate this. So for example, in some centres, a social worker or nurse may visit the school and explain to other children about cancer. As all Health Services come under pressure to justify expenditure, it is important to know whether these activities really improve things for the children. Again, QOL is the most obvious outcome to evaluate.



Our current work involves a longitudinal study that focuses on how QOL changes during the first 2 years after diagnosis. We hope that this information will be especially useful for parents of newly diagnosed children, because it will give them an idea about how their child might react during the course of treatment. Simply knowing what to expect may be helpful, but will also enable families to plan more effectively.

We are very pleased to hear from Parent Groups or individuals about their own experiences. Further information is available on our web-site:

www.shef.ac.uk/childfamilyresearch

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Luxembourg 2001

Experience of a Parents' Group in Argentina

Presentation at ICCCPO Meeting in Luxembourg, Sept. 2001

Brief History

■ Startup

- Founded and launched operations in 1994
- Started with a budget of US\$12,000
- original staff: 2 founders and 1 volunteer
- Exclusive focus on editing and publishing pediatric cancer information booklets
- 25 families

■ Today

- Annual budget of over US\$ 100,000
- 7 permanent staff and over 60 volunteers
- New house: play centre for children and attention center for parents
- 500 families

Argentina's Socioeconomic Context

- High degree of economic activity, concentration in Buenos Aires area (50%)
- High unemployment rates since 1995 (above 15%)
- Migration from other states to Buenos Aires
- Illegal immigration from neighbor countries to Buenos Aires
- Long distances

Healthcare System in Argentina

- Fragmented health care system
- Childhood cancer treatment only available in main urban centres (Buenos Aires, Cordoba, Mendoza)
- National law enforces free delivery of chemotherapeutic agents only.

Main Programs

- Information and Education
- Emotional Support
- Social Support
- Recreation and Entertainment
- Communication
- Recruiting of Volunteers

Information and Education Program:

- Free distribution of booklets to all institutions, professionals and people involved with pediatric cancer patients.

- Workshops for teachers and students to inform them about cancer, to enhance children's acceptance of their suffering and to reduce the sense of isolation imposed by cancer.
- Consulting to develop emotional and social support programs in hospitals of other states of the country.
- Scholarships for nurses.

Published Bibliography

- Before we started our project, no printed information related to the childhood cancer was available to the general public
- More than 55,000 books have been distributed free all over the country
- Main distribution channels are hospitals and our institution
- Up to now, 13 different titles have been published

Social Support Program

- Consulting about community resources, such as free public transportation, state grants, etc.
- Sharing information and ways to deal with common problems
- Gathering of specific drugs and cancer treatment devices (wheelchairs, catheter, cellular phones)
- Emergency Fund
- Advocating for families in legal and health security issues
- Development of a blood and platelet donor database.
- Basic needs.

Key Incoming Challenges

- Adapt the current organization to the pattern of the increasing demand
- Improve efficiency of current operations
- Improve the quality of the relationship between our organisation and health and government institutions
- Integrate with international organisation.

Visit us at: www.fundacionflexer.org

Edith Grynspancholo
Fundacion Natali Dafne Flexer
Buenos Aires, Argentina

News from parent groups

P.A.V.E.L. - A Romanian association for parents of children with cancer

Romania with its most outstanding nature and soil (which many countries would envy) with both knowledge and skills in various domains, with its Christian orthodox faith that could move mountains, still fails to feed, shelter and care for its over 22 million people.

Romania is a challenge for those who live there and those who come and go - visiting tourists or working volunteers helping to build a Romanian society. The challenge consists in dealing philosophically and practically with the differences between intentions and outcome, between the rich and the poor, between the decision makers and the ordinary citizens, between those who have the power to change the society for the better and those who hope for the change. In 1989 many walls fell, crushing ideologies and mentalities, changing passivity into vitally needed social actions. After ten years of democracy, Romania is still in search of its identity.

To this day, Romania's problem to take care of its children remains a public issue. The response from western Europe was enormous and voluntary aid efforts by individuals, by newly formed or established charities brought a flood of aid to this country to assist children in their desperate position.

Ten years have gone by. Today there are far less charities and voluntary efforts involved, but those who remained have become better organized, more competent and certainly more determined to stay and work until the problems are gone. Assisted in many places by western voluntary efforts, the situation for children improved in many respects such as housing, food and education.

Unfortunately there are also downsides such as a powerful economic recession, problems of malnutrition and failure of paying the staff. Other downsides remain strictly clear: namely the continued poverty which forces ordinary Romanians into a situation where they hardly can cope with daily life. Followed by the deterioration of their health, with poor support from the health and social care services.

There are major difficulties in pediatric oncology. Some of them are:

Totally insufficient funding from the national health budget, very often insufficient medication supplies, poor supportive care due to low standards of blood products and modern antibiotics as well as immunoglobulines or antiviral and antimycotic drugs. Often there are no cytogenetic or molecular biology laboratories. And there is a shortage of medical equipment, instruments for analysis or any

Dear Ms. Marianne Naafs-Wilstra!

We apologize for our late answer. For a long while we still had hope that we would be able to take part in the meeting of parents' organizations in Luxemburg, but unfortunately we were not able to raise any money for our representatives to go there. But we think the money we have now is more needed for the treatment of the children, which, praise God, goes quite successfully now.

In Kiev, the capital of the Ukraine, they've started performing operations of bone-marrow transplantation, and we are getting ready to send some children there for the operation.

Fortunately, we are not completely isolated: this spring we had a chance to take part in a Russian-French seminar in Moscow on helping children with difficult forms of diseases. Now we know personally and keep in touch with parents' and voluntary organizations from Moscow and St.-Petersburg and some other cities who help children.

A few days ago we have received from you by regular mail one more bulletin by ICCCP. Thank you so much! We hope to keep updated by you on other meetings, and on your current news.

With deep respect,
Eugene & Marina Novitsky,
coordinators of "Parents' Initiative"
hemato@simfi.net

modern apparatus. Hygienic, sanitary and nutritional circumstances are bad and standard of living is low.

Yet there are a lot of doctors and medical personnel well educated and trained who, despite these circumstances try heroically to save the lives of? The national Center of Statistics registered in the year 1997 482 new the small patients.

Children with cancer or leukemia in Romania don't have the same chances for cure as children in better equipped countries. The recovery rate is very low - less than 20%. How much pain is hiding behind this number? The National Center of Statistics registered in 1997 482 new cases of cancer patients under 18 years. And in the year 1998 399 children died from cancer including leukemia.

To fight this situation, a group of parents founded a small non-governmental organization for children with cancer and other blood diseases, which in May 1996 was legalized as the association PAVEL, meaning "Receiving Help - Life is Bright".

Its purpose is to offer moral, material and juridical help to parents of children with cancer. We often noticed that, whenever children get such a serious disease, their parents become desperate and hopeless. They find themselves in a hospital atmosphere which is often foreign to them, especially with the medical terminology. The parents' despair is increased by other factors like the lack of medicines in and their high costs. Lack of adequate equipment or special laboratories, the difficulty to offer a proper diet or better food during and after the treatment of the child, lack of knowledge about the respective disease, its causes, its treatment, sometimes lack of communication between the child's doctor or nurse and the parents, lack of information about a number of things.

The association PAVEL wants to meet many of these needs and has succeeded already in several ways:

Through PAVEL several institutions (hospitals, associations, orphanages, churches) and people received help such as medication, furniture, medical equipment, food, clothes, toys.

The Parent House was opened in 1998 and it houses the parents who come to Bucharest for the treatment of their children free of costs.

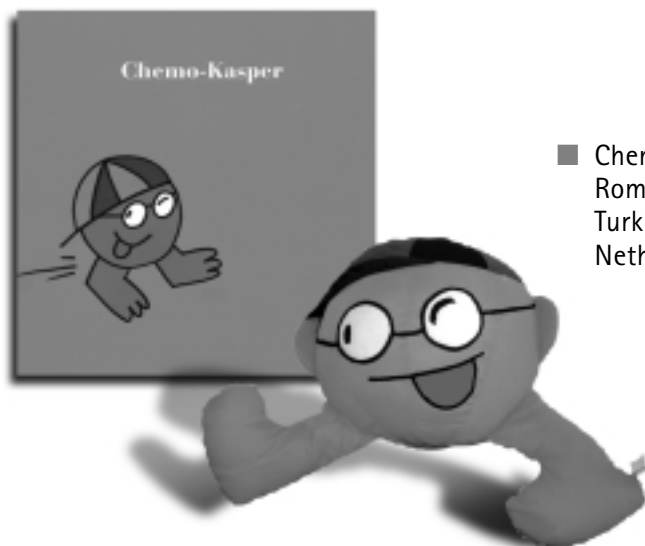
The association

- is supplying parents with food (weekly for one year - or as long as the child is in treatment)
- It helps parents to contact different hospital and clinics and fights to get the medication
- It published several booklets and picture books for children
- It organizes festivities in the hospital such as Christmas or Easter celebrations

All this was realized with the kind help of other foundations, organizations or companies from Holland, France, Germany, England, Canada and Romania. But also thanks to the fight and the efforts of a small, very well intended and active group of people from PAVEL, most of them volunteers (in the majority parents or close relatives of children with cancer) who struggle in their private life like all other Romanians.

We are always trying to improve the conditions of the hospitals in order to save the lives of the young patients, who have a right to live and enjoy life like any other child. We are looking to establish connections with other groups to improve the situation in our hospitals. Through ICCCPPO it will be possible. A Romanian philosopher and priest once said: "Give and you will get". Through ICCCPPO we can all get a lot.

Olga Rodica Ionescu
Association P.A.V.E.L.
e-mail: pavel_romania@hotmail.com



- Chemo-Kasper – booklet is now available in Romanian (through Pavel, Romania), and in Turkish and Arabic (through VOKK, Netherlands, bureau@vokk.nl).

"Hope" Holiday in Chelyabinsk



The public association «the Hematologists of the World to Children», joining together doctors and parents of children, suffering from oncology diseases, is going to conduct a holiday for those children, who have won in fatal gripper with illness.

We invite you to take part in a celebration, which is to be held on November 16, 2001 at 12.00 a.m. in the Center of business cooperation.

We hope, that you will share with us our common joy.



Chelyabinsk area, unfortunately, is not most favorable for life of the person because of a heavy ecological situation. The payment for a civilization are the human lives, including our babies.

The awful illness tried to steal the most precious belongings of the parents: their children. But, joining our attempts, children, their parents, doctors, the medical sisters, have stood.

Now more than 500 children celebrate their second birth.

We want to give hope to those people who still struggle and require support. Due to successes of modern medicine, it became possible for the majority of sick children.

Rita Galipova,
454076, Chelyabinsk, Medgorodok, - ODKB, Cancer and Hematological centre.
Ph. (3512) 34-03-01, 65-80-19
Fax (3512) 60-89-90
E-mail: mopob@chel.surnet.ru

Note: Rita Galipova was announced women of the year for her district in 2001.



SAINT SILUAN*

WARNING SIGNS FOR CANCER IN CHILDREN

- S:** Seek: Medical help early for persistent symptoms
- I:** Eye: White spot in the eye, new squint, blindness, bulging eyeball
- L:** Lump: Abdomen and pelvis, head and neck, limbs, testes, glands
- U:** Unexplained: Fever, loss of weight and appetite, pallor, fatigue, easy bruising or bleeding
- A:** Aching: Bones, joints, back, and easy fractures
- N:** Neurological signs: Change in behaviour, balance, gait, and milestones, headache, enlarging head

*Saint Siluan was a Russian monk who died on Mount Athos in 1938. He prayed ceaselessly for all humanity.

This list has been compiled by the
South African Children's Cancer Study Group

Children's Cancer Help Line



toil-free 0800-333-555
(weekdays 08h00 - 16h00)

The warning signs were developed by CHOC, South Africa, and adopted by ICCCPPO and SIOP.

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