



## **Initiation of a Parents' Organization in a Developing Country**

**Summary of the round table discussion at the PODC Committee of SIOP at the 32nd SIOP Congress in Amsterdam, October 5, 2000.**

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**Chair persons:** G. Bode (Germany) and HP. Wagner (Switzerland).

### **Introduction**

The development of pediatric oncology (PO) starts with the establishment of a pediatric cancer unit (PCU), a referral center for a pediatric population of one to several millions. The PCU is the heart of a local PO network consisting, besides the PCU, of peripheral satellites cooperating closely with the PCU, a "triage" system at the "front" and a transport system for good risk patients. In addition to this local network a national network will be developed to coordinate the local networks and to defend the interests of children with cancer and their families. Parents' organizations play an important role in both networks.

### **Status of Pediatric Oncology in Different Countries**

In very poor countries PO has no priority. With decreasing mortality rates (cumulative risk to die during the first 5 years of life <10%), cancer emerges as a leading cause of death in children over five years of age. Within the same country cultural and socioeconomic differences influence the access to care: the biggest obstacle is poverty which is always associated with lack of education, poor hygiene and unemployment. Parents who understand that childhood cancer is curable in 3 out of 4 patients, but who are too poor to pay for an adequate treatment, suffer the most.

### **Motives to Start a Parents' Organization**

Destitution, despair and bitterness are important motives for parents, families and friends of children with cancer to cooperate. It may help parents to learn what others have done to cope with practical and emotional difficulties: where to stay; buy drugs and food; what to say to the child, siblings, grandparents and teachers; how to speak to doctors and nurses. Lack of competent, comprehensible and comprehensive information or insufficient palliative care and, of course, the desire to do something for the deceased child are other strong motifs.

### **Who initiates a Parent's Organization?**

In Yogyakarta (Indonesia) parents of surviving leukemic children were the promoters of a Parent Association of Leukemia Children. In Jakarta the Indonesian Childhood Cancer Foundation was initiated with the goal to offer Indonesian children with cancer the same chances Dutch children have. At the Johannesburg Hospital in South Africa energetic catalysts were needed to bring up the parents association of the Children's Hematology and Oncology Clinics that spread over the whole country. In Recife (Northern Brazil), a psychologist and the head of a division of PO initiated, in 1985, a center offering housing and other support to parents of children with cancer coming from far. In Romania an organization set up by despairing parents, in 1996, is providing housing, drugs, medical and practical information and for the poorest cloths, shoes and sometimes food.

## **What are the Goals of Young Parents' Organizations?**

Besides providing shelter, drugs and transportation, parents' organizations, by forming therapeutic alliances with the hospital staff, can help the parents and patients to understand the disease and to actively participate in the treatment; they can assist in the difficult transition from curative to palliative treatment and advise families after the death of their child. Parents' organizations can do a lot for the patient and his/her siblings:

they can assist in training, organize baby sitting, camps, theaters and can provide, for older patients, individualized help to obtain optimum professional formation.

Parents' organizations play a pivotal role in advertising that cancer is curable and that the majority of survivors are to be considered as normal, with a normal working capacity and life expectancy.

On the national level representatives can, by cooperating with other parents' groups, lobby for the interests of children with cancer, by demonstrating for example that to treat good risk cancer patients may not cost more than to treat other diseases.

Parents' groups can contribute to the formation of PO specialists (medical and non-medical) and help to finance staff positions.

## **When Should Parents' Groups be Set up?**

As soon as PO activities start at a PCU, it is time to set up a parents' organization to support the parents of recently diagnosed children with cancer but also to assist the PCU in its daily activities. It is important that there is close cooperation between the hospital staff and the parents' organization. If the PO structures get more complicated specialized parents' groups may be formed, according to the needs of children with cancer in a given country.

## **Pitfalls**

If parents' organizations comprise only parents they may lack stability. It may therefore be wise to include motivated volunteers and to encourage them to become active members, according to their special skills and know how. In order to become efficient, parents' groups must be structured and have bylaws. They may cooperate with other organizations that support children with cancer, e.g. Cancer Leagues, Support Groups for Chronically Ill Children, Child Health Institutes, National and International Governmental and Non-Governmental Institutions such as WHO, UICC, INCTR etc.. In order to avoid pitfalls, twinning of well-established and new parents' organizations might be helpful.

## **Discussion from the Floor**

In Alexandria (Egypt) physicians have successfully initiated parents' organizations. For well-conceived projects more sponsors are available than anticipated.