

## Contributions of the Association P.A.V.E.L. in the implementation of the European Standards of Care for Children with Cancer, in Romania

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**A. Short presentation:** Association P.A.V.E.L. is the Romanian association of parents of children with cancer, which was founded on May 10, 1996, with the aim to improve the life quality of children with cancer and their families. Association P.A.V.E.L. is member of: UICC, ECPC, ICCCP, IAP, HOPE, EUROCHILD aisbl and APSR.

The association is running the following programs:

- Public information on the pediatric oncology, with the aim to increase the awareness within patients, families, public opinion and state or private institutions;
- Program of psychological and social support (aimed to patients and /or relatives, including free housing, when needed);
- Play therapy program;
- Respiro programs in or outside hospital (cultural and relaxing activities for patients);
- Socialization and recovery programs for survivors (camps, trips, etc.);
- Prevention, awareness and humanitarian campaigns
- Advocacy and lobby for different issues concerning the problems of children and young people with cancer
- Improving the infrastructure in pediatric oncology departments in Bucharest (equipment, park for children in the hospital yard, etc.)

### Projects approved starting with January 2012

- **Hospital School** – pilot program for children and teens who had to abandon the school because of long hospitalizations, thus remaining outside of the educational system
- **“Center for occupational therapy and vocational counseling for children and young people ill/survivors of cancer”** 01.10.2011 – 31.12.2012, budget 13.996 Euro, with the

following objectives:

**Ob. 1** Prevention of the school interruption and securing the access to education for 75 children with cancer, patients of the Oncology Institute of Bucharest or Fundeni Clinic Institute, coming from poor families, with minor physical/mental deficiencies caused by illness and by the long time spent in hospital.

**Ob. 2** Increasing the chances of integration in the professional and social life and decreasing the dependency of the social support network for 55 young patients of the Oncology Institute Prof. Dr. Alexandru Trestioreanu of Bucharest and Fundeni Clinic Institute coming from poor families, with minor physical/mental deficiencies caused by illness and by the long time spent in hospital.

### **B. The weaknesses of the Romanian health care system.**

Given the experience of more than 15 years of Association P.A.V.E.L. in the field of cancer in children and young people, we can list the following **weaknesses of the Romanian health care system**:

- a) the absence or the weakness of the prevention services, which are not available with a well-established action plan;
- b) the late diagnosis of the oncologic conditions in children/young people, a fact that has a major impact on the survival rates;
- c) lack of a national cancer register for children/young people diagnosed with oncologic conditions;
- d) lack of monitoring the evolution of cases after the patients leaves the medical institution where he/she is treated;
- c) the parallelism between social and medical services (they do not come together for a common action);
- d) lack of working standards for the intervention of a multidisciplinary team;
- e) lack of a long term intervention model (case management type), involving coherent actions, orientated according to clear objectives agreed by the patient and specialists, with the participation of families, of the formal support network (institutions: school, hospital, DGASPC, SPS, etc.) and informal (friends, neighbors, etc.);
- f) lack of a legislation centered upon the child with cancer and establishing the institutional and personal responsibilities;

- g) lack of a proper dialogue between associations of patients and the state institutions involved in the decisions regarding the patients needs;
- h) lack of medicines, meaning a death sentence for children and despair for their families;
- i) lack of an educational and professional integration plan for children with oncologic diagnosis and the person who stays with them in the hospital;
- j) lack of funds special dedicated to programs (projects) for children with cancer (we do not have financial support from the state; funding is scarce and in small amounts, which means that the patients NGOs can hardly survive. The specialists they hire and train are constantly threatened to lose their job. In the absence funding, NGOs are forced to face the challenge of survival and they cannot make long term strategies).

### **C. What did we do in this situation:**

Concerning the Oncology Institute of Bucharest, the state secured medical services have integrated in a certain extent with those provided by patients associations, establishing a multidisciplinary team formed by:

- The attending doctor, chief nurse and nurse - employed by the hospital in the pediatric oncology ward;
- Other health care professionals, with complementary specialties: radiation therapy specialist (existing in the same medical institution), pediatric surgeon (who works in different medical institutions, usually children hospitals) and kineto - therapist (working also in other medical institutions, specialized in recovery);
- Social assistant, psychologist and play therapist, hired by Association P.A.V.E.L.;
- Volunteers (members of different associations) who have a very important role in creating a concrete support network for each patient;
- Social services existing at community level in the community of origin of the patient and family/extended family.

### **The fiability of the multidisciplinary team in present**

In general, the case manager in assisting the little patients is the attending doctor. Relations and communication between specialists within the same medical institution are, in general, good, but there are some difficulties in accessing services provided in other location. In situations of transfer or release from the hospital, the communication role is taken over by a family member, and the specialists of the multidisciplinary team act only in emergency cases or in case that

there is not a family member able to represent at the optimum level the child's superior interest. This lapses appear because of the under numbering of the state paid staff (there still is a small number of specialists for a large number of patients) and because of the incapacity of the NGOs to provide services as long as there are needed. Therefore, the cases of the patients with the most vulnerability criteria are prioritized, in order to solve the specific problems. The plans of common intervention are discussed, usually, in the day when the attending doctor is on call (with the whole team taking part, if the members have time) and the task to reevaluate and monitor the case is the responsibility of the social worker and of the chief nurse.

### **Results obtained:**

- Approximately 170 families with a child with cancer benefit yearly of the social services; this leads to the improvement of the social and material situation of the family and to securing optimum life conditions for the little patient, in order to respond to the treatment and heal. In 2010, the spending of the Association P.A.V.E.L. for food, transportation, medicines, medical investigations and some medical equipment (prosthetics, catheters) surpassed the amount of 23.000 Euro (minimum wage in Romania being approximately 150 euros). In addition to the direct financial support for patients and their families, hired staff and volunteers of the association promoted the social cases in the media (TV appearances, articles in printed press) or in other communities (youth organizations, financial groups with a big financial power, etc.), in order to solve the problems and to increase the life expectations of the small patient.
- Starting with 1998, P.A.V.E.L. Parents House in Bucharest hosted more than unique 570 beneficiaries (children, parents, relatives, etc.), meaning more than 1500 hosting's. In that way, children and young people ill benefited from the support of their family, during treatment and between cures;
- Within one year, approximately 154 children/young people and persons accompanying them (usually, their mothers) benefit from the psychological counseling programs (individual and group sessions) during the time they are in the hospital; in a therapeutically environment, the little patients and their mothers are helped to become aware of their inner resources and to use them in the fight against the illness;
- Within the program of play therapy, run in the ply room P.A.V.E.L. (pediatric oncology department, 5th floor), in 2010 more than 140 children benefited from the play therapy services, with 1983 entrances. On one hand, the patients where helped to get to a psychological and emotional balance, with a positive role in the response to the treatment, and on the other hand they benefited of an environment proper for the normal development of their personality.

Other activities of P.A.V.E.L. Association:

- increasing the awareness of the public and of the specialists in the medical field, of the social workers, business people and media (TV shows, conferences, website, and publications)
- promoting the patients' rights (signing of petitions, speaking in front of the authorities, involvement in ASPR, etc.)

#### **D. Future projects:**

- Dissemination of our association experience and of a good practices pattern for other hospitals /organizations (guides, leaflets, meetings, conferences);
- Development of **social economics** workshops for survivors and their families; this project would constitute a continuation of the project "Occupational Therapy and Vocational Counseling Center", representing an alternative in the efforts of the association to self-sustain;
- **Creation of a camp for patients** which, in addition to the relaxation-socialization function, could function as a therapeutically community (a place for informal meetings of patients and specialists, in order to exchange ideas, improve the working manner and facilitate the communication, for a greater involvement and a better knowledge of problems of both sides);
- Expanding the specialists team in order to obtain a better **monitoring** of patients after the treatment cure in the hospital.