



JOLANTA KWASNIEWSKA'S FOUNDATION
Communication Without Barriers

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Childhood cancer - why we should be doing more for our children?

I was offered to say a few words about "Why we should do more for our children". I would like to answer this question:

- because children are our joy, love and hope;
- because they are weak and vulnerable - and are not allowed to defend their rights to health, life, happiness;
- we cannot be the observer of their suffering;
- because the measure of humanity is our attitude to people who need our help and support;
- they make us feel important, needed, endowed with unlimited love and trust;
- children will form and create our future, and they have influence on the world which we are building now;
- children count on us, if we disappoint them, they will no longer trust people;
- the number of specialists (psycho-oncologists) with experience in working with children and youth is still too low;
- there is no system of monitoring late outcomes of cancer.

My Foundation “Communication without Barriers” has paid most of its attention to children’s needs and expectations. The needs of those in whose interest we have decided to work are well known to me. Personally, I followed many children and the meetings with them will stay in my mind forever.

We receive a lot of appeals for help in saving the lives and health of young patients, supporting hospitals, hospices, rehabilitation centers, and individual children. For twelve years we have tried to help, carrying aid for children with cancer. We have created situations

in which even the most seriously ill children can be happy and safe. These moments help children to overcome difficult situations in hospital ward.

Important events and actions:

Giving additional equipment support for pediatric units

It was in the interest of quality of life of children and adolescents with leukemia that we bought for our first earned money, four transplant beds for a Clinic in Wroclaw. It was a social need; it was a need of children with leukemia.

The Foundation "Communication Without Barriers" gave all thirteen highly specialized Hematology and Oncology Clinics positioned throughout Poland financial support for their expansion, the purchase of specialized equipment and for medicines.

The programme: Butterfly Hospitals

For seriously ill children, to give them the strength and the motivation to fight for their own health and life, we have redecorated the gray-white of the Polish pediatric units into a fairy-tale world. We know that the success of a treatment depends largely on the mental health of a child. Till now we have changed nearly 600 children clinics, hospital words or outpatient clinics!

Building the Clinic of Oncology and Hematology

The greatest achievement hitherto of our Foundation is the funding of the building of a modern Clinic of Oncology and Hematology in Gdansk, which opened in 2005. This Clinic is housed in a building especially designed for its needs; it was constructed according to the current standards required for a highly specialized treatment of seriously-ill children as well as for the improvement of the conditions needed for a better functioning of both the doctors and the technical staff as well as the parents of the small patients. The designers also looked after the interiors and, as a result, with wonderful paintings they created a unique fairy tale world which is so much conducive to the treatment of children and helps them to recover much faster. It has a ward with 37 beds, an outpatient clinic, three laboratories, an EKG operating theatre, accommodation for parents to spend the night and a small kitchen.

My work was noticed and appreciated by ECPC. As patron of ECPC, it worries me that **the matter of children and adolescents with cancer are not adequately supported, nor adequately considered, and that there are no solutions for financial security.** We should devote more attention to this group and to this issue. The situation of children and adolescents with cancer is improving, but it remains a system of care which does not protect many of the needs of this group of patients. Many of the problems it faces remain unresolved.

Time is against the children in our care

- a very high number of children is taking the treatment in highly specialized centers in the advanced stage of disease,
- there are still too few oncologists who specialize in working with children,

- there is no monitoring system for the after-effects of the treatment of children's cancer.

Annually in Europe about 20 000 children and adolescents aged 0-19, are diagnosed with cancer. Approximately 80% of these patients currently manage to complete the treatment - only provided that they have access to a proper and comprehensive multidisciplinary team.

Every minute and every second is important for children, and every minute must be worth living. This quality of life is every day ensured primarily by the love and care of the family. The role of the family at the stage of the diagnosis, the care, during and after the treatment plays a vital role, but its potential is still too little used.

European Standards of Care for Children with Cancer

After two years of planning and preparation we have just managed to finish a document - prepared under the direction of Professor Jerzy Kowalczyk, National Consultant in the Field of Hematology and Oncology - which contains all the information needed to create the proper care of children with cancer in the European Union.

The symposium took place on **14 October in Warsaw** at the **initiative of the Foundation "Communication Without Barriers"**. Poland did a first step in creating a partnership to fight against cancer. Continuation of the work initiated at the Symposium will contribute in the near future to a significant increase in the number of children and adolescents diagnosed in the early stages of the disease and to a better quality of life during and after the treatment. We hope that this symposium will also be a first step in making changes in the current system of treatment and the process of diagnosing in the European Union and furthermore will provide an appropriate psychological, social and household support and create conditions for proper mental and physical development.

The interest in our initiative has been tremendous; the patronage on the Symposium was taken by Androulla Vassiliou, European Union Health Commissioner. The Symposium was attended by many prominent guests and leading European child oncologists. The main goal of the symposium was to discuss the complementary document describing a common system of care for children with cancer in the EU. The task for today is implementing the National Oncology Programmes that meet the standards of cancer care for children in order to ensure that all children with cancer have an equal opportunity to overcome the disease and to participate fully in society.

"Many things we need - can wait. A child cannot. Right now child's bones are forming, creates blood, mind. We cannot say tomorrow, his name is today. "