

NURDOR

National Childhood Cancer Parent Association

IT'S TIME FOR CUP OF CONVERSATION

November 2011/May 2012



Wishing to help families of children cured from cancer and to give answers to numerous questions of interest, we have initiated the project of psycho-social aid titled "The time for cup of conversaton". The project has been initiated in cooperation with doctors, psychologists and medical staff at the childrens` hemato-oncological departments, with the idea that through various workshops for families (**ask the doctor, psychological workshop, ask the medical staff, nutricionist for you, social security rights and parent to parent and creative and fun workshops**), we try together to faciltate their stay at the clinics.

One of the important items was to help parents and children to get answers and to share with professional staff and with each other, their most important worries and fears, and to ease them the stay at the clinic.

The main goal of the project is to offer useful information to parents related to cure of childrens` malignity, as well to enable them through group support and open talks, to decrease the stressful emotions, which may negatively influence the outcome of the illness. The aim of the project is also to raise the level of the public awariness on children malignant illnesses and to engage all potentials of the society (material and moral) to help children and their families to get all the help they need to return to the social community as valuable members, able to contribute to the society`s further development. Special segment of the activity is aimed to getting support of the public for the purpose of the authorised state bodies to employ pshychologist on each of the hemato-oncological department, as well as to employ greater number of doctors and other specialists on these departments which would, inter alia, improve informing of parents on the desease.

LEADERS` PSYCHO-SOCIAL SUPPORT

All lecturers and workshop leaders have the significant experience in the field of individual and group work and rendering of medical and psycho-social support to vulnerable groups. Their experience, sensibility and empathy represent the basis of their work, since it is confirmed in practice that the support to the family system represents the most efficient mode of intervention. During the health treatments, they empower families and prepare them for normal functioning and inclusion in normal life streams through the educative lectures, workshops and support groups. During family workshops, kids are organized in creative workshops run by volunteers specially educated to work with children being cured from malignant diseases. Furthermore, workshops were held also in the Parents Houses in Belgrade and Novi Sad.



Headed by the idea that this type of support should be provided to all parents during curement of their children, we have decided to run the project on two more hemato-oncology departments, to ensure equal form of support and help to all families. Threfore, workshops were held at the following hemato-oncology departments:

Institute for Health protection of children and youth of Vojvodina, Novi Sad – IZZZDIOV
Children Clinic, Niš – KDIB
Department of Pediatric Oncology, Institute for Onkology and radiology of Serbia - IORS
University Children`s Clinic in Tiršova street – UDK



WORKSHOPS REALIZED AT FOUR HEMATO-ONCOLOGY DEPARTMENTS



“What we have managed to achieve within the “The time for cup of conversation” project is invaluable for all families, parents and children, as well for us as the Association. We have recognized the need for this form of psycho-social support and we are realizing it successfully for two years“, said Ms. Branislava Penov, the main coordinator of the project and continues:

“We are proud to be able to ease the cure of children and therefore the family, in the following ways:

- Easier acceptance of cancer diagnosis by parents;
- Decrease of parents` tensions;
- Decrease of children`s and parents` anxiety;
- Strengthening of life activities despite the illness and after the illness;
- Improved informing of parents on the curement process and patients rights;

THE WORD OF THE DOCTOR

The best indicator on the success of each workshop is a smile on the faces of mothers when the workshop has been finalized. Each workshop is slightly tensed at the beginning, more like the official lecture and the introduction on the planned topic. Then, mothers start to get included, trying to transfer (each from her own angle and in her own way) their experience to others.

During this exchange of experiences and emotions mothers get to know each other, they manage to open doors of empathy and the need to help and cooperate with others. Each time at one moment we see the same - tension disappears and relaxed communication starts on different subjects, even those that are not related on the subject matter of the workshop.

At the end, workshops look like mingling of the best friends at the coffee shop, so the workshops tend to last longer than envisaged.

I believe this type of work with mothers is very good, because it not only enables mothers to have moments out of the hospital rooms (not only physical), but it also helps them to form a small community based on support and understanding they share for the same problem and based on the feeling they are not left alone.

I do support the education work with mothers and with whole families for the purpose of better understanding, acceptance and resolving of problems related to curement of the child. *The time for cup of conversation Project* is excellent both for the children and the parents. The workshop has fulfilled all expectations, even exceeded them.

This Project is good in so many ways, children have the opportunity to spend two hours having fun with very good volunteers without presence of parents, and mothers to talk on topics of their interest with adequate persons. Workshop approach enables parents and children to bond even more, to share their positive and negative feelings, to exchange their thoughts and experiences.

Parents have expressed their wish the Project should be run throughout the year and workshop hours should be extended (although the workshop always lasted for two hours)



Prim. dr Vesna Bogičević
Children's Clinic, Niš

MINGLING WITH KIDS AT THE DEPARTMENT



Within the project of the psycho-social aid that we have had at the hemato-oncological departments of the children's` clinics, we have run the fun and creative workshops for children.

During parents` workshops, children used to spent time with excellent, young volunteers, who have tried to make them happy, investing all of their positive energy and good humor. Crayons, markers, picture books, books, toys, various social games are to be found at each workshop“. Children were drawing, we read them stories, and they were always eager to have fun, so the workshop time passed very quickly”, pointed out Sandra, our long term volunteer and one of the coordinators of “The time for cup of conversation” Project.



During the seven months of the Project, volunteers have donated over 500 hours

of spending time with children, and in return, have received hundreds of smiles which, they say, will warm their hearts forever!



PARENT TO PARENT

My child has been diagnosed nine years ago and then the completely new life has started for two of us. The life consisted of constant visitation of the hospital, the hemato-oncology department. Now, I am approaching the hospital again I have to enter the same department, but now as person who should give hope to parents whose children are in the curement process. I know so well what they are feeling, what they are thinking about, and what they are expecting from me. I should be their shining example that the recovery is possible and that the struggle is not in vain. I am aware that my task is not an easy one, but I am also aware how much it would have meant for me then (9 years ago) to have in front of me the parent who had already passed the path that me and my child were supposed to pass, but I did not have ... and that`s the reason why I am here today, at the the Clinic. This is „The cup of conversation” Project in the PARENT TO PARENT form. The goal is fulfilled because my appearance has brought to parents hope of better tomorrow and the possibility of recovery, which is the most important. They have felt the support and understanding and the great feeling that we are not left alone.



IMPRESSIONS OF A PSYCHOLOGIST



The new workshop type of work with mothers, leaded by professionals, I consider extremely useful and beneficial. Naimly, the aim of psychological workshops is definately to allow moms to express their thoughts, concerns, positive and negative feelings, and to recognize them and exchange with other moms and psychologist. It has shown in practice that these workshops are extremely effective for moms in initials phase of curement, as they are still in the state of shock and disbelief. They should recognize their fears, disbelief and to share their thoughts in order to understand they are not alone and that they have the group that will support them and enable to adapt to the new situation as painless as possible. Of course, there has been a lot of tears, but also a lot of smiles and exchange of good energy when the curement starts and the first good results start to show. During the time we have noticed it is important for moms to go out of hospital rooms (both physically and mentally) and to know that someone is taking care of their children, and finally of them also.

Slađana Veličković, psychologist
Childrens` s Clinic, Niš

RESULTS ACHIEVED

„The time for cup of conversation“ Project has lasted for **9 months** (from November to June).

During the Project we have held the total of **104 tematskih workshops**, because the whole Project is envisaged that a multidisciplinary team, depending of the needs and specifics of each department, gives lectures – workshops within one cycle. During one cycle of lectures – workshops, lecturers were the doctor, psychologist, parent, medical nurse, nutricionist and social worker. The Project is realized at the four hemato-oncology departments that cure children from various malignant diseases.

We have managed to include in workshops the total of **505 parents** (some took part several times), while **423** persons have filled-in the questionnaire based on which we have managed to get requested data.

Venue	Number of examinees	Percentage
IORS	146	34.5
UDK	66	15.6
KDIB	82	19.4
IZZDIOV	129	30.5
Total	423	100

Leader	Number of examinees	Percentage
doctor	90	21.3
psychologist	116	27.4
nutricionist	36	8.5
medical staff	49	11.6
parent	93	22
social worker	39	9.2
Total	423	100

Based on statistical analysis of evaluation lists that have been filled-in anonymously after each workshop by parents, the average total grade of all workshops is excellent, and amounts to **4.84**.

These data show that **84.1%** of all parents, participants at the workshops, have graded lectures with excellent grade, **10.77%** of parents graded 4, while **1.54%** of them graded 3.

IMPRESSIONS OF THE PARENTS

At four clinics where we have realized the Project, we have held the total of 104 workshops.

Table 1. shows the total number of workshops of certain type at each of the clinics:

- 27 workshops—psychologist;
- 25 workshops—parent;
- 21 workshop—doctor;
- 17 workshops—medical staff;
- 7 workshops—nutricionists;
- 7 workshops—social worker;

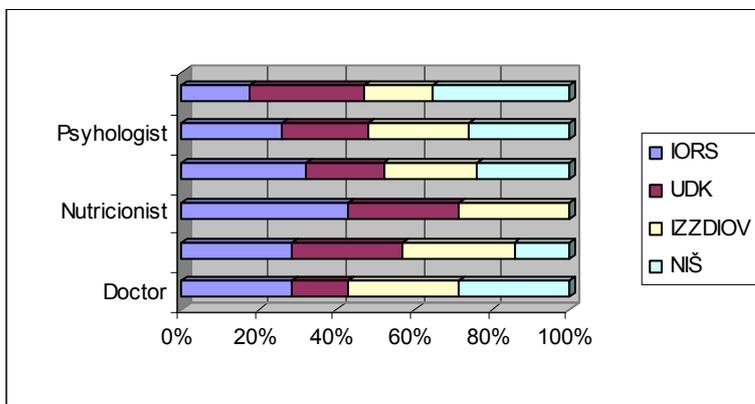


Table 1.

From Table 2. it is possible to see that the greatest interest, judging by attendance, parents have shown for workshops run by psychologists (27.4%) and “Parent to Parent” workshops (22%).

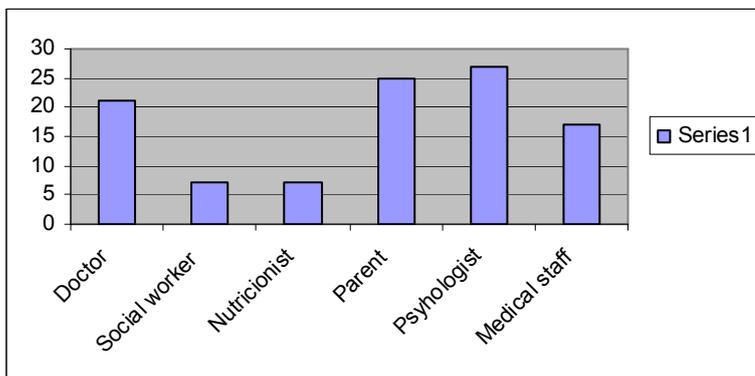


Table 2.

Comments, suggestions and personal impressions of parents are extremely important and speak more than figures.

Very good and useful project for children and parents.

Thank you for helping children and parents to persist in struggle with this disease.

The excellent way to make parents confident.

In questionnaires, for the question: What I Like the Most, we have received answers that will be important as guidelines for planning the next cycle:

Commitment of the doctor to each of the parent

Open conversation with the psychologist

How to distract thoughts of children in positive way

Honest conversation on illness

Humanity

Evaluation, comments and statistical data that are the result of evaluation of this cycle of “The time for cup of conversaton” Project, speak in favour of restarting of the Project, evenmore for its continuous implementation. Therefore:

On our behalf and on behalf of our parents and children, at the end of this second cycle, we would like to warmly thank all professionals, volunteers and donors that have enabled realization of this Project. We are looking forward to realization of the next cycle!

WE WOULD LIKE TO THANK ...

We would like to thank all those who have helped us to realize *The time for cup of conversation* Project, and firstly to:

Merck Sharp & Dohme company and B92 Fund, who have financially supported the realization of the Project in the amount of 589,640 dinars.



Results we have achieved are of extreme importance. What is even more important is that we have achieved, thanks to great number of people, to support parents and children at the hospital departments, through workshops, where our leaders and volunteers have donated their smiles, positive energy and enthusiasm. We would like to thank also all people who have took part in all activities organized by *Nurdor* and provided donations, and therefore helped to realize this Project and obtain psycho-social aid to families and children cured at the clinics in Serbia.

NURDOR PUBLICATIONS AS THE RESULT OF TWO CYCLES OF THE PROJECT



NURDOR, the National Association of Parents of Children with Cancer, www.nurdor.org.rs, is a nonprofit, nonpartisan, nongovernmental organization founded by parents of cured or deceased children, the medical staff of oncology departments, and volunteers who recognized the need for systematic and effective support for parents of children with cancer. The National Association began its work in 2004, and it brings together parents and friends of children from all over Serbia. The main objective of the organization is to support families of children with cancer by providing high quality treatment, rehabilitation and socialization of children, infected or healed. NURDOR is a member of the International Confederation of Childhood Cancer Parent Organizations (ICCCPO), www.icccpo.org and works closely with the International Society of Oncology Pediatrics (SIOP), www.siop.nl.

NURDOR's bank account, where you can send your donations at Unicredit Bank, is **170003001071500082**.



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