

Awareness for early detection of childhood cancer – the Romanian model

by Olga Cridland, Association P.A.V.E.L.



Project Idea and Context

The need for a targeted information and education on pediatric cancer early detection in Romania is proved by the very low survival rate versus rates in other European countries, in large part due to late diagnosis of the cancers.

The parents' information and pediatricians' very low knowledge about the early warning signs and symptoms resulted in delayed referral to a physician for early diagnosis of the child disease. In addition, there was no strong, long-term and collaborative relationship between the non profits and health and social local public authorities that would set some premises for increase awareness and run consistent and high impact public campaigns on cancer matter.



This project consisted of an awareness and information campaign which included: translation and adaptation of materials, brochures, leaflets, large distribution and dissemination of the information, regional workshops and conferences, public communications.

This was the first such campaign of prevention and awareness addressed to parents, but also to primary medical staff, educators, social workers, media, .. in Romania.

The timeline for the project, with duration of 4 months, was 1.07.2010 – 31.10.2010, interim report on 1-st September 2010, final report on 15-th November 2010.

The project was funded by UICC Building Capacity Fund.



Goals and Objectives

The main objectives of the project were:

1. To develop a package of specific informational materials on childhood cancer with focus on importance of warning signs and early detection addressed to parents and pediatricians
2. To widely distribute the information in four region of the country
3. To run awareness campaign through workshops, conferences and media

Our goal was to offer parents and pediatricians the right information for a right and prompt decision regarding the potential risk of childhood cancer, to prevent delays and misleading of diagnose.



We were targeting to provide a baseline level of knowledge needed for parental information on childhood cancer, to provide pediatricians with information's and materials in order to improve early detection of pediatric cancers, by correctly recognizing and responding to warning signs and symptoms.

Implementation Sites

Curtea de Arges and Campulung Muscel (Arges county), Buzau (Buzau county), Giurgiu (Giurgiu county), Ramnicu Valcea (Valcea county) and Bucharest



Activities and Resources

The project activities were carried out through the P.A.V.E.L. Resource and Services Center for children with cancer, functioning inside Oncologic Institute of Bucharest as part of a partnership agreement between P.A.V.E.L. Association and the institute.

The Chief Medical Doctor, Conf. Dr. Monica Dragomir from the onco pediatric ward of this institute was consulted regarding all the information and invited to take part at the project events, as well as other two oncologists.

Human Resources:

Project officer - Olga Cridland, 2/3 time; Project assistant – Camelia Demeter, 2/3 time; Financial coordinator – Iuliana Stana, 1/4 time; consultants and speakers: Conf. Dr. Monica Dragomir, Dr. Silvia Ilie, Dr. Anca Colita (oncologists); volunteers: Dana Hadareanu (translation and press release), Carmen Sava (graphic design and editing), Alexandru Halalau, Frank Cridland, Cosmin Halmagi .



Our starting activities of the project were focus on setting the package of informational materials to be distributed during awareness campaign. This package consisted of translated and adapted brochures, leaflets, articles, posters. The materials were selected and approved by consulting the specialists mentioned, edited and printed.

The material for media was prepared and contacts for release, publishing and support were set.

To manage the wide distribution of the materials and to run an effective awareness campaign we contacted community institutions, parents and pediatricians organization in four regions of the country to ensure a working network for support.

We aimed to spread the informative materials at the level of community's pediatrician's offices, schools and other institutions dealing with families with children.

The awareness campaign consisted of 5 workshops for pediatricians and community representatives, conference, press releases, internet and other communication tools identified with community's organizations.



Stakeholders, Partners, Participants

We have worked with the Oncologic Institute "Prof. Dr. Alex. Trestioreanu" from Bucharest.

In addition, we received great support from Giurgiu Mayor Office, Association Sf. Sava Buzau, Association PROVITA Giurgiu and Public Health Authority, General Direction for Social Assistance and Child Protection, Health County Insurance House and Local Education Inspectorate, local and national media from five towns (Buzau, Campulung, Curtea de Arges, Giurgiu, Rm. Valcea) from four counties (Arges, Buzau, Giurgiu and Valcea) and from Bucharest where the workshops and the Conference were organized.

As media partner we were supported by Sanatatea (Health) Press Group.



Beneficiaries

Direct / Indirect Beneficiaries

Direct 200 Indirect 50,000

Beneficiary Participation

The topics reached at the 5 workshops and at the conference of the campaign were mainly about early detection and cancer prevention. However, the topics raised a large debate and constructive discussion about Association PAVEL, other NGO s involved, cancer treatment, legislation.

The participants at these workshops and conference, as well as media have informed further on the public: parents, medical staff, social workers, educators, journalists about the importance of the early childhood cancer detection and what are the signs and symptoms of childhood cancers.

The journalists supported this awareness campaign with 39 articles (9 on written media, 2 presentations at TV and 28 on-line) and supported PAVEL Association to be more visible and appreciated in our community.



Results

O.1. To develop a package of specific informational materials on childhood cancer with focus on importance of warning signs and early detection addressed to parents and pediatricians.

The informational package was printed as follows: 2.000 brochures, 1.500 leaflets and 500 posters. All these materials acknowledge the support from UICC. The materials were used and distributed to all participants at the 5 workshops and one Conference.

The package for campaign consisted of two brochures, three leaflets and one poster (from UICC funds) and other 3 sorts of leaflets and 2 sorts of posters (from PAVEL funds)

O.2. To widely distribute the information in four region of the country.



Centrul de Resurse și Servicii P.A.V.E.L.
 (În incinta Institutului Oncologic
 "Prof. Dr. Alexandru Trestioreanu", parter, camera 116)
 Șoseaua Fundeni Nr. 252 Sector 2, București
 Tel/fax: (021) 311 27 00
 www.asociatiapavel.ro

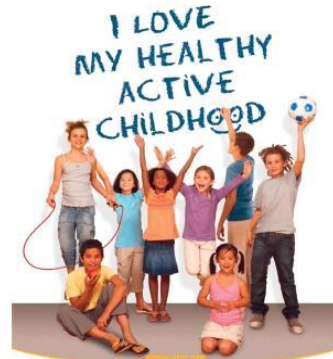
CANCER Help Line: 0 800 800 421

Informare, asistență și consiliere pentru pacienții
 cu cancer (copii și tineri) și familiile lor

**SEMNE DE ALARMĂ PENTRU PREVENIREA
 CANCERULUI LA COPII**

SAINT SILUAN - calugăr rus, care s-a rugat neîncetat pentru toți oamenii
S: SEEK (Rău) Stare de rău: ajutor medical la timp, pentru simptome
 persistente
I: EYE (Ochi) Pată albă pe ochi, orbire, bulboare, strângere din ochi -
 persistent
L: LUMP (Nodul) Umflătură în una din zonele: abdomen, pelvis, testicole,
 cap, gât, membre sau glande
U: UNEXPLAINED (Inexplicabil) Febră, pierderea greutatei, a poftei de
 mâncare, paloare, oboseală, sângerari, apariția de vânătăi
A: ACHING (Dureri) Dureri de oase, încheieturi și spate, fracturare cu
 ușurință a oaselor
N: NEUROLOGICAL SIGNS (Neurologie) Schimbare în compartiment,
 pierdere echilibrului, dificultăți de mers, dureri de cap, mărirea capului

Această listă a fost făcută de către:
 South African Children's Cancer Study Group



**SEMNE ALE CANCERULUI
 LA COPII, ADOLESCENȚI ȘI TINERI**

Adaptare după "Signs of Childhood Cancer"
 From Ped - Onc Resource Center
 Resources and information for parents of children with cancer... by parents of
 children with cancer.

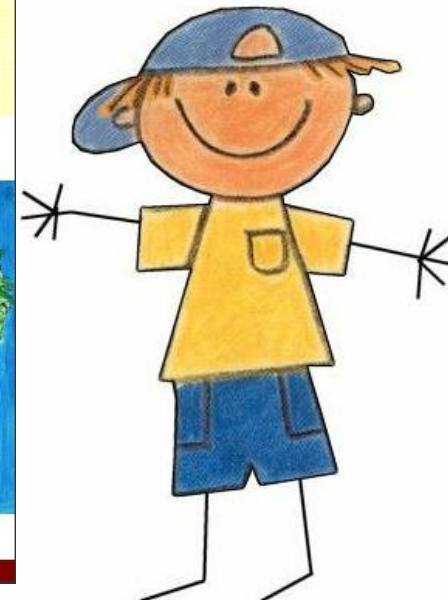


**SEMNE ALE CANCERULUI LA COPII,
 ADOLESCENȚI ȘI TINERI**

adapted from "Signs of Childhood
 Cancer"
 from Ped - Onc Resource Center
 Resources and information for parents of
 children with cancer . . . by parents of
 children with cancer

**CANCERUL LA COPII,
 ADOLESCENȚI ȘI
 TINERI**
**Algoritmi de trimitere
 adresati asistentei
 primare**

adapted from "Referral
 guidelines for suspected
 cancer" (NICE)



SAINT SILVIAN
SEMNE DE ALARMA PENTRU PREVENIREA
CANCERULUI LA COPII

- S:** **Skull (Cap)** - Stare de mare agitat medical la timp pentru capotarea persistenta
- R:** **Eye (Ochi)** - Pata alba pe ochi, eritem, iridociclov, crengues de ochi, punctiuni
- L:** **Lump (Nodul)** - Umflatura in zona abdomenului, pubis, testicului, cap, gat, membru, glande
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- N:** **Neurological signs (Semne neurologice)** - Schimbarea in comportament, pierderea echilibrului, difuziuni de mers, amorți de cap, surzenie auzului

Planul Siliu a fost dezvoltat ca parte a unui proiect finanțat de către UICC și este un instrument pentru țări în dezvoltare.
Asociația Siliu și Fundația Siliu de către South African Children's Cancer Study Group
Asociația P.A.V.E.L. - asociația părinților cu copii bolnavi de cancer. Întâlniți-vă cu alții în grup.

CHCC Childhood Cancer Centre
www.asociatiapavel.ro

UICC
global cancer control

Aveti intrebari? Sunati, va rugam, de luni pana vineri (intre orele 10 - 16) la:
TELVERDE: 0 800 800 421

ROMTELECOM



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Tel: +4 021 346 84 80 (Casa Parintilor)
E-mail: pavel_romania@yahoo.com

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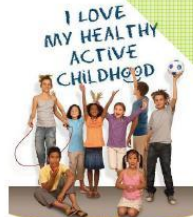


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Va rugam, directionati 2% din impozitul pe venit către Asociația P.A.V.E.L.
Cod fiscal: 8956076

Donati și sponsorizați se pot face în conturile:
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CONT USD: RO48BPOS71003031332USD01
CONT EURO: RO48BPOS71003031332EUR01

deschise la BANC POST S.A., Sucursala TITAN, RO-7000, București

Asociația P.A.V.E.L.
Asociația părinților cu copii bolnavi de cancer, leucemii și anemii grave



CANCERUL LA COPII SI TINERI

Semne pentru depistarea timpurie și recomandari

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SEMNE DE ALARMA PENTRU PREVENIREA
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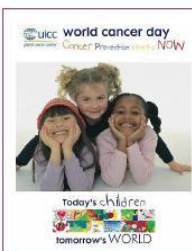
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Asociația P.A.V.E.L.

Asociația părinților cu copii bolnavi de cancer, leucemii și anemii grave



CANCERUL LA COPII SI TINERI

SEMNE PENTRU DEPISTAREA TIMPURIE SI RECOMANDARI

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SEMNE DE ALARMA

pentru depistarea timpurie a
cancerului la copii și tineri



Aveți întrebări?
TELVERDE: 0 800 800 421
De luni până vineri 10⁰⁰-16⁰⁰

Asociația P.A.V.E.L.
Asociația părinților cu copii bolnavi de cancer,
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Tel: +40-21 346 84 80 (Casa Părinților)

E-mail: pavel_romania@yahoo.com
www.asociatiapavel.ro

UICC

The International Union Against Cancer

- Paloare și/sau oboseală extremă.
- Nervozitate.
- Febră inexplicabilă.
- Vânătași inexplicabile.
- Infecții persistente sau recurente ale sinusurilor, nasului și/sau gâtului.
- Ganglioni limfatici umflați (axilar sau supraclavicular).
- Dureri inexplicabile ale oaselor.
- Dureri persistente ale spatelui.
- Dureri de cap persistente, asociate cu vărsături.
- Stare de conștiință alterată.
- Lesinuri sau convulsii.
- Creștere anormală a capului mișcări anormale ale capului și/sau oculare.
- Lipsa reacției vizuale (nu mai urmărește stimulii vizuali).
- Un ochi sau ambii ochi împinși înainte.
- Reflex pupilar alb; acest lucru poate fi observat în fotografii, în care ochii apar albi.
- Strabism nou instalat sau o schimbare a acuității vizuale.
- Tulburări de mers (mers anormal sau schiopătat), de percepție și de echilibru.
- Inexplicabile scăderi ale performanțelor școlare sau neatingerea unor standarde de dezvoltare.
- Schimbări inexplicabile ale comportamentului sau ale dispoziției.
- Oprirea sau regresia dezvoltării motorii.



Campania de Conştientizare

Asupra Semnelor și Simptomelor
Cancerului la Copii



Seminar

Lector: Conf. Dr. Monica Dragomir
Sef Sectie Oncopediatrie, Institutul Oncologic, Bucuresti

Centrul Cultural Local Ion Vinea

Giurgiu

27 Septembrie 2010: 12.30-14.00

Intrare libera

Organizator
Asociația PAVE.L



www.asocatiapavel.ro

Uniunea Internațională
Contra Cancerului



www.uicc.org



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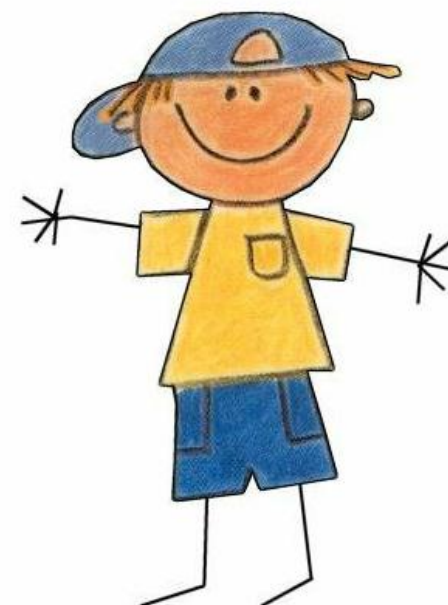
- S:** **Seek (Rau)** Stare de rau: ajutor medical la timp pentru simptome persistente
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Sfantul Siluan a fost un calugar rus, care a murit pe Muntele Atoș, in 1938.
El s-a rugat neincetat pentru toti oamenii.

Aceasta lista a fost intocmita de catre:
South African Children's Cancer Study Group
Asociatia P.A.V.E.L. - asociatia parintilor cu copii bolnavi
de cancer, leucemii sau anemii grave



www.asociatiapavel.home.ro



O3. To run awareness campaign through workshops, conference and media

Association PAVEL identified four areas where local authorities and local organization eagerly welcome the workshops and actually they were involved in supporting and organizing these meetings.

These were as follows: Curtea de Arges and Campulung Muscel (Arges county), Buzau (Buzau county), Giurgiu (Giurgiu county) and Ramnicu Valcea (Valcea county).

Parents, medical staff, representatives from local authorities in charge with children protection and welfare, populate these seminars. The topics reached at these workshops were mainly about early detection and cancer prevention.

However, the topics raised a large debate and constructive discussion about Association PAVEL, other NGOs involved, cancer treatment, legislation. In addition, the information about the materials and seminars were disseminated via internet. Besides the five workshops, we organized a Conference in Bucharest.



Sustainability

a) The most important outcome of the project is extend access to information regarding early childhood detection for parents and pediatricians; more than 150 persons attended workshops and 80 persons attended the Conference.

From the direct participants and thanks to the information materials (posters, leaflets, booklets) and media coverage, a large number of people were better informed about the signs and symptoms of childhood cancer, but also about other issues as: possible causes of cancer, types of childhood cancers, treatments, other recommendations for a healthy living,



b) The topics reached at the 5 workshops and at the conference of the campaign raised a large debate and constructive discussion about Association PAVEL, other NGOs involved, cancer treatment, legislation. The conclusions of the workshops will be used to initiate other information materials and tools, for ongoing awareness activities.

In addition, the information about the materials and workshops was disseminated via internet to a large number of individuals and organizations who are connected with cancer or health matter.

Other consequences:

- The increased number of parents (with a ill child with cancer) well informed about the services and programs offered by Association P.A.V.E.L.
- On long term, the early diagnose of cancer at children and thus, the reduction of the heavy treatments and costs, the reduction of the number of deaths at children and young people with cancer.



Workshop Giurgiu, Giurgiu County, presentations by Dr. Monica Dragomir and Olga Cridland, 27th of September 2010



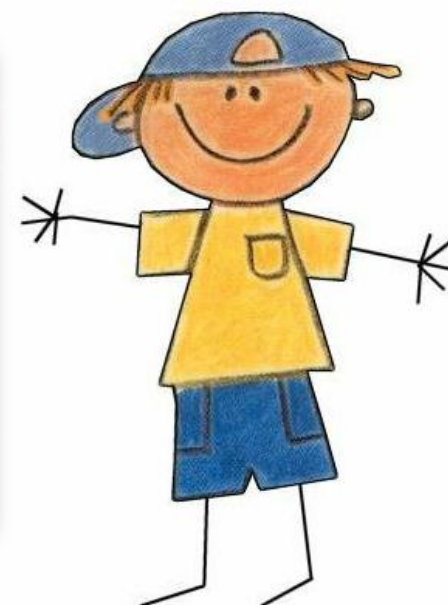
Workshop Campulung Muscel, Arges County, presentations by Dr. Silvia Ilie and Olga Cridland, 30th of September, 2010



Workshop Curtea de Arges, Arges County, presentations by Dr. Silvia Ilie and Olga Cridland, 30th of September, 2010



Workshop Ramnicu Valcea, Valcea County, presentations by Dr. Silvia Ilie and Olga Cridland, 30th of September, 2010



Workshop Buzau, Buzau county, presentations by Dr. Monica Dragomir and Olga Cridland, 4th of October 2010



Interactive Press Release Conference, Bucharest
Speakers: Dr. Monica Dragomir, Dr. Anca Colita, Olga Cridland, Alina Mitroi and 4 survivors: Iulia, Raluca, Vladimir and Daniel
9th of November 2010





Survivors and public speaking





Who is Association P.A.V.E.L. ?

P.A.V.E.L. (Getting Help, Life Is Bright) is an association (NGO) for parents with children who suffer from cancer, leukemia or grave anemia. It was founded in order to improve the lives of children and young people with cancer, leukemia or grave anemia by providing information, moral, psychological and material support and also to sustain the specialty clinics.

P.A.V.E.L. Association is member of: **ICCCPO** (International Confederation of Childhood Cancer Parent Organizations), **UICC** (International Union Against Cancer), **ECPC** (European Cancer Patient Coalition), **IAPO** (International Alliance of Patients' Organizations), **HOPE** (Hospital Organization of Pedagogues in Europe), member associate of **SIOPE** (an European organization of nurses and doctors in pediatric oncology) , member of **FABC** (Romanian Federation of Cancer Patients' Associations) and member of **Alianta pentru Sanatate din Romania**.



At the present, the association is involved in various activities and offers services financially supported by companies, individuals and different organizations.

Starting with 2008 many of P.A.V.E.L.'s activities have been accredited.

Human resources: we have now 17 people employed and have 10 constant volunteers and more, in certain activities.

Up to now P.A.V.E.L. Association offered a variety of services for children, youth with cancer and their parents:

- Liaison between parents and hospitals abroad for treatment, including free of charge treatment for children
- CANCER Helpline
- Play and art therapy for > 800 children
- Free accommodation for > 1500 parents with children under treatment, but also adult patients
- Various events during holidays (camps, trips, exhibitions,..), participation of the survivors at international events



- Support for families in clothes, toys, drugs, money.
- Financially support for the ill children for buying missing medicines and for paying medical investigations
- Improving conditions in hospitals through donations in furniture, equipment, drugs.
- Relaxation places for children and parents (gardens, play rooms)
- Advocacy for subsidized drugs, improved conditions in hospitals, trained personnel for counseling
- Psycho - therapeutic, spiritual and educational support for the young patient and their parents
- Legal counseling, information and guidance services
- Resource Center with trained personnel for art and play therapy, counseling and psychological support.
- Hospital school from 1st of September 2012 for children and teens from two major hospital from Bucharest, Fundeni Clinic Institute (hematology ward) and Oncologic Institute (oncology ward)



- P.A.V.E.L. has organized prevention and humanitarian campaigns
- Publishing brochures and leaflets informing people about cancer, patients' rights, diet and preventive measures.
- P.A.V.E.L. has organized national conferences in pediatric oncology and hematology in 2010, 2011 and 2012.

In 2012, the conference was: 'The Multidisciplinary Assistance of Children and Teenagers with Cancer'; its aim: to identify concrete solutions in order to improve the situation of children and young people with cancer in Romania, by matching the four entities involved: authorities – doctors – patient associations - companies



Appreciation for the activities of the Organization:

- The prize for “Project of the Association with the greatest addressability”, Medica Festivity – III rd edition, 2011;
- The “Prize for the Most Implicated Association of Patients”, at the Sanatatea TV Festivity, on the 4th of December, 2008;



Key objectives for next TWO years (e.g. operational regions, projects in planning)

- To develop reference and information materials and to organize prevention campaigns.
- To ensure continuity of the services we are already providing.
- Capacity building of the association.
- To train specialized personnel in delivering educational, emotional and psychological support, art and play therapy sessions.
- To promote a specific legislation and good practices system in the field hospital school.
- To create a hospital teachers and pedagogues network in Romania, affiliated at international organization in the field.
- To create a camp site for sick children, adolescents and survivors.
- To build a Resource and Educational Center and a guest house for parents near the Oncologic Institute in order to ensure stability of services.
- To open a second guest house in Bucharest for the parents that have children and adolescents hospitalized in Oncology wards.



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THANK YOU

