

MARIA SPYRAKI — Member of the European Parliament

CHILDHOOD CANCER

The Battle We Can Win



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ΕΚΔΟΣΕΙΣ ΤΖΙΟΛΑ
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The book you are holding is the minutes of one discussion that we aspire to be the beginning for the creation of a registry for pediatric cancer in Greece. The pediatric cancer registry's scope is to share knowledge, experience, and data for science to rise to the challenge and help us win this battle.

————— Dedicated to Polyxeni and Sophia —————

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INTRODUCTION

Maria Spyraiki

Member of the European Parliament



September has been recognized by the European Parliament, on the initiative of the European People's Party, as the awareness month for the treatment of pediatric cancer. In this context and under my capacity as the only MEP from Greece who is a full member at the BECA Committee, I co-organized in cooperation with the Chairman of the Panhellenic Medical Association Thanasis Exadaktylos and the Rector of the National and Kapodistrian University of Athens, Thanos Dimopoulos, an open online event on the 30th of September under the title **“Childhood and Adolescence Cancer Awareness Month: A battle that we can win” will be open to everyone.** The discussion was the outset for launching a dialogue platform on pediatric cancer in Greece and setting a measurable goal: The establishment of a pediatric cancer registry that will facilitate science and raise the possibilities to have more and more victories in this battle.

As you will read in the following suggestions, the numbers highlight all aspects of the problem. Starting from the unpleasant elements, approximately 250,000 children globally are diagnosed with cancer each year. Of these, only 20% can access proper medical care. Especially in Europe, 20 children lose their lives every day from a different type of cancer, with the most common being the Hodgkin's disease with 16.1%, gonadal tumors (GCT) with 15.2%, brain tumors with 10%, Non-Hodgkin lymphoma with 7.6%, thyroid cancer with 7.2%, malignant melanoma with 7% and Acute Lymphoblastic Leukemia (ALL) with 6.4%. However, the positive element that we can keep is that 70%-80% of these children who have access to specialized medical treatment manage to overcome the disease due to medical science's progress, the adequacy in terms of medicaments, and the qualified scientific personnel. So, the little fighters that have won against cancer now amount to 500,000 in Europe and 400,000 in the United States. It is estimated that by the end of this year, one out 350 adults will have developed and survived from some form of cancer during childhood or adolescence, a rate that is expected to increase even more in the future.

Pediatric cancer is often considered invisible cancer. Our aim and primary concern, both if we held and in the ongoing committee work of BECA in the European Parliament of which I am a member, is to make it visible. A significant percentage of cancer cases stem from potentially preventable causes. Each passing year adds new, powerful, and effective "weapons" to scientists' hands in the fight against childhood and adolescent cancer. This means that the scope of action in the European Union is enormous. At the legislative level, BECA has been commissioned with the formulation of a plan against cancer, which will include horizontal legislative measures aimed at prevention, amplification of access to medicines and treatments, and the increase of patients' life expectancy, for children with cancer to achieve a complete cure, without outer complications and problems.

It is true that when cancer affects a person, it also affects the whole family, especially when the patient is a child or an adolescent. By opening up the discussion and highlighting the difficulties that our young patients and their families face, we shed light on the areas that require intervention, with the contribution of the constant progress of medical research and the specialization of healthcare scientists, the tireless activity of associations and non-governmental organizations (NGOs), the digital technology with the collaboration and transfer of best practices in an international level, as our speakers competently analyze in the presentations that will follow. After all, cancer is a vital health issue that will directly affect 40% of EU citizens with a significant impact, not only towards the European health systems and economies but also towards the daily lives of the families called upon to deal with it.

It may sound trivial, but the truth is that only the battle that was not fought is lost. And the fight against childhood cancer is a fight that we want, can, and must give to win against cancer.

For our families.

For our children.



Dr. Athanasios A. Exadaktylos

Chairman of Panhellenic Medical Association



Welcome Speech of the Chairman of Panhellenic Medical Association.

It is estimated that every year 250.000 children worldwide suffer from various types of cancer, while approximately 8.600 new diagnoses occur only in the USA. In our country, about 300 children are affected every year by cancer, with the most common type of it being leukemia.

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But despite these alarming numbers concerning the affected children by cancer, the survival rate is high since, currently, more than 70% of the children affected by cancer manage to survive in the USA.

Nevertheless, cancer is responsible for most deaths compared to any other disease during the school and pre-school age, after traffic accidents.

The most common cancer in childhood is leukemia, responsible for about one-third of cancers in children.

In terms of frequency (responsible for about 20% of childhood cancers), the second type of cancer is the malignant brain tumor, while many more are following.

The causes of cancer remain unknown, and the diagnosis falls as a “bomb” inside the families, which persistently ask doctors if they were in any way responsible for this unfortunate event.

There is one thing about which parents should be immediately informed, and that is that all children’s cancers are cured or respond in the same way to treatments as the cancers of adults, while they possess a considerably higher rate of cure. Also, the hopes that they will not be deprived of their child are high.

However, the suffering caused to the child, the parents, the siblings, the grandparents, the uncles, and each one close to the family, is immeasurable.

Both the states, insurance companies, the healthcare systems, and the medical community must address the efficiency and sensitivity of this ordeal by explaining every aspect of the child’s condition and treatment. The psychological support coming from young and older adults is essential not only during the stage of diagnosis but also during the treatment stage and the recuperation stage.

I wish you the best of luck with your work.



Prof. Thanos Dimopoulos

Rector of the National and Kapodistrian University of Athens



SALUTATION FOR THE CHILDREN'S CANCER DAY 30.09.2020

As a Professor of Hematology-Oncology in the Hematology-Oncology Unit of the University Clinic of “Alexandra” Hospital and the Eugenides Hospital of the University of Athens, I deal daily with many dozens of cases that need chemotherapy or clinical evaluation and treatment advice. Cancer is the second leading cause of death in developed countries, after cardiovascular disease, and in our country is responsible for about 25,000 deaths annually. Young adults, usually over 18 years old, also come to our Clinic, while the younger ones are treated in the Pediatric Hospitals, and their large majority in our country (approximately 80%) in the Pediatric Oncology Unit “Marianna V. Vardinogianni - ELPIDA.”

Pediatric cancer is rare, with the most common types being leukemias, lymphomas, and central nervous system cancer. It has also had lower mortality rates in recent decades, with 80% of children surviving more than five years from diagnosis due to effective treatment and early diagnosis. Nevertheless, it is a primary cause of death in this “tender” age of the child and adolescent, significantly reducing survival expectations, as many years of life are lost. In our country, about 400-500 children are diagnosed with cancer every year, while in the USA, the new diagnoses are about 11,000.

Childhood and adolescent cancer treatment can follow various protocols through chemotherapy, radiotherapy, surgery, immunotherapy, and bone marrow transplantation. Here, I want to highlight the enormous effort in this area for bone marrow donation so that its heterologous transplantation is another treatment of choice. Already, the fact that more than 100,000 samples have been voluntarily collected from the bone marrow donor banks, the majority through “Orama Elpidas,” inspires confidence that our compatriots stand by the side of children with cancer who need it.

The protocols for the treatment of childhood and adolescent cancer are quite different from those we follow in the treatment of adults. For this reason, we need specialized pediatric oncology departments, with pediatricians specialized in hematological and oncological diseases. In addition to specialized hematologists and oncologists, we have hired specialized staff, nursing psychologists, psychiatrists, pediatric neurologists and child psychiatrists, social workers, pediatric radiotherapists, surgeons, and others. At the same time, because childhood cancer is one of the “rare diseases,” there is a significant number of clinical trials with innovative drugs that require a large number of patients to evaluate their efficacy and safety and to be administered globally, with the result being that there is a need for physicians to be aware of the importance of conducting clinical trials for these diseases.

Finally, an essential parameter for childhood and adolescent cancer in Greece and internationally are the so-called “childhood cancer survivors,” i.e., children, adolescents, and adults who have now been cured of childhood cancer. They now need a society that will provide them with an individualized approach to the problems that may remain from this disease (e.g., disability - loss of a limb) or the side effects of chemotherapy and radiation therapy (e.g., reduced ejection to cardiac function, psychology), etc. For all these reasons, the cooperation of all relevant bodies in creating a corresponding pediatric cancer registry, accelerating clinical trials for new, more effective, and safer treatments, and generally highlighting these children and their families’ needs is an essential priority for all of us.



Διοργάνωση:



ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ
Εθνικό και Καποδιστριακό
Πανεπιστήμιο Αθηνών

Marianna V. Vardinoyannis

*UNESCO Goodwill Ambassador and President of ELPIDA Association
of Friends of Children with Cancer*



Ladies and gentlemen,

I feel great joy but also great emotion to participate in this important initiative.

An Awareness Initiative on Childhood Cancer, a challenging subject to which I have devoted much of my life and work.

“A battle we can win”. I believe the title of this virtual conference is now closer to reality than ever before.

My experience in the field of childhood cancer began in 1990 when there was no infrastructure in Greece and the word “cancer” was covered by deep prejudice.

Thirty years later, everything is different.

We have our Oncology Hospital, one of the best in Europe. The rates of childhood cancer cure are now impressive since 3 out of 4 of our children are being cured and Greek society has embraced children suffering from cancer and their families.

This process was not easy nor self-evident.

The whole family of “ELPIDA” worked all these years tirelessly to achieve the goal we had set from the beginning “not to lose a single child, while it can be saved.”

We recently inaugurated the state-of-the-art “Cell and Gene Therapy Center”, which offers hope even in the most difficult cases of childhood cancer. At the same time, the significant increase in the number of volunteer bone marrow donors, through the “ORAMA ELPIDAS” Association, allows even more children to find a compatible donor.

This course of 30 years, especially the smiles of parents and children who did it, really makes me believe that, yes, childhood cancer is a battle we can and must win.

With the help of science which has made tremendous progress, medical community, and social solidarity, I believe we can all do it together!

So with the hope of a better future without borders in children’s health, I welcome this Conference.

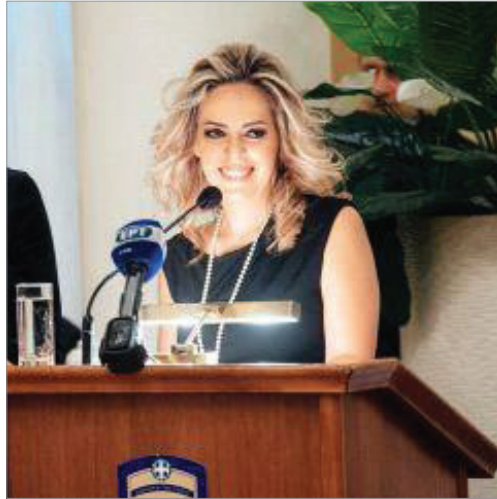
I congratulate Mrs. Maria Spyraiki, Mr. Exadaktylos, and Mr. Dimopoulos for their initiative, which is another step in the fight against childhood cancer that fills our hearts with hope!

Thank you very much!



Anastasia Stamatea

President of the “Pisti” Association



It is the highest social obligation to offer to children. All together.

The work of the “Pisti” Association very briefly, but purposefully:

We, the parents who were at the “Agia Sofia” Children’s Hospital, wanted to face the daily problems together. Thus, at the beginning of 1993, PISTI was created.

Our goal is to assist doctors, nurses, and other staff of the Hematology-Oncology Clinics and the Bone Marrow Transplant Unit.

To achieve the above objectives, we have hired specialized staff. More specifically, we have hired psychologists, social workers, and an occupational therapist for the psychosocial support of children and their families.

This group works daily in all three clinics of the Pediatric Oncology Unit “Marianna Vardinogianni-Elpida” of the Children’s Hospital “Agia Sofia.”

In recent years, we have been able to provide the hospital with a geneticist, Mr. Glentis, who contributes with his very specialized knowledge to perform genome analyzes.

14 Of course, we should mention that the staff of “Pisti” is dynamically supported by a group of remarkable volunteers, who contribute significantly to the work of our Association.

The board of “Pisti” consists of 7 members, all parents of children who have fought the disease. Let me mention them one by one; they are friends; they are companions in the life struggle we give for all children.

George Tamboureas, Vassilis Neratzakis, Themis Chalkias, Vasiliki Alevizou, Tassos Vlachos, Dimitris Alexandropoulos, and, of course, all the other active parents of the club.

“The value of volunteering and social contribution.”

The comparative advantages of social contributions are unlimited. Our Association does not replace the state but cooperates and complements through cooperation. The individual experience of the people of the clubs and the empathy of the volunteers are transformed into active action. Social contribution volunteers have the flexibility, and by activating both the private and the public sector, they achieve practical solutions to urgent issues.

We are all members of “civil society,” we talk, we cooperate, we are the link between public authorities and citizens for the benefit of the latter. All those who put themselves at the most vulnerable groups’ service are the living proof of the value of individual responsibility to defend the collective interest. We all do this every day; individual responsibility has always been essential and primary to us.

Especially during this period of the pandemic. Our role is maximized.

We are here now, today, but also at every moment to activate all the healthy forces, to awaken, and to highlight the role of supply and solidarity.

The Covid era’s challenges require us to look for new ways to strengthen our work and alternative models of volunteer mobilization. We need a more focused approach and even greater cooperation in the light of a holistic strategy around childhood cancer. New issues emerge every day (anxiety, uncertainty, fear, ignorance, the fronts are many). We have to adapt.

We are here today to represent the pillars that support the fight against childhood and adolescent cancer. What I would like to highlight this message here today is the value of mutual support and cooperation.

This is the hope and strength of our children. Let us not forget that these are the most vulnerable population groups and the future of our world. Research has shown that social sensitivity increased during the pandemic, and we need to cultivate this further.

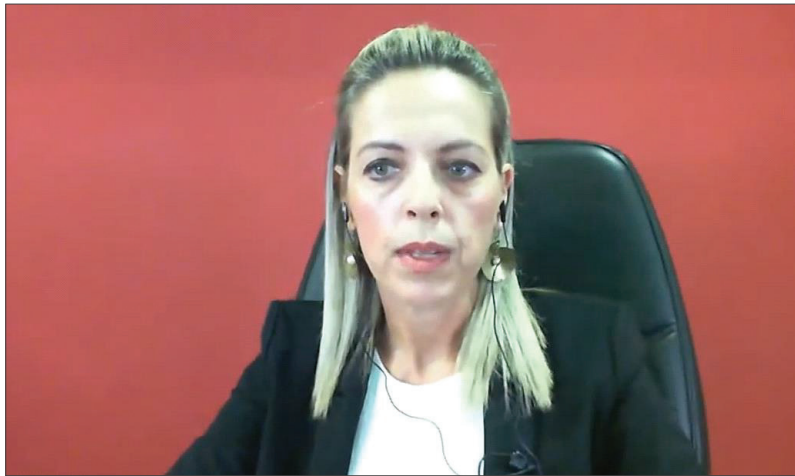
The main problem is that the pandemic interrupted the traditional methods of communication of the work of the clubs (sports-cultural events), which were part of the financial resources. There is an urgent need for new practices to attract volunteers and funding from competent bodies.

I feel the need to thank Ms. Spyraiki for her exceptional initiative to highlight the issues of childhood and adolescent cancer through this meeting that takes place under this peculiar regime.

Warm thanks to you, Rector and President of Panhellenic Medical Association.

Mrs. Vardinogianni, every time I am with you, I feel special gratitude and joy because you always make sure to have us under your auspices. Your international radiance and your work for the suffering people is an example and a model for everyone.

At the same time, I consider it my duty to thank our Hospital manager, Mr. Papasavva, the directors of our clinics, Mr. Kattami, Mrs. Kitra, Mrs. Polychronopoulou, as well as all the doctors and nurses who frame the Oncology Department, for their non-stop offer.



Menia Koukougiani

Founder - CEO

NGO KARKINAKI, Awareness for Childhood and Adolescent Cancer and Board Member of PanEuropean Network for Care of Survivors after Childhood and Adolescent Cancer.



The NGO “KARKINAKI” was created exclusively by parents of children with cancer, with a dual goal: on the one hand, to fill the vast public information gap on childhood and adolescent cancer and the other hand, to actively support families facing the illness.

About one child gets cancer every day in Greece. KARKINAKI transports the difficult daily life experienced by these children’s families to the whole world, informs about the ways of their support, undertakes initiatives and actions to make their everyday life more sustainable, either in the hospital or at home, or during treatment after or after it.

From the simplest things, e.g., hand hygiene that ensures the reduction of infections that endanger even the lives of children under treatment, up to the most complex, such as the contribution to the proper functioning of Pediatric Clinics and the promotion of clinical research in our country, KARKINAKI demands intervention and substantial contribution to the effort of childhood and adolescent cancer not only to cease to be a taboo subject, but to find as many eyes and as

many hearts as possible open and willing to help every child with the disease to have access to a high-level hospitalization, effective treatment and, ultimately, the right to life.

Cancer is the leading cause of death for children over one year of age in Europe. It is estimated that there are 500,000 cancer survivors in childhood.

Children and adolescents with cancer have specific problems in their treatment that differ from those of adults.

A vital requirement of the European Organizations for Childhood and Adolescent Cancer is that the European Cancer Action Plan (Europe Beating Cancer Plan) includes a separate chapter on Pediatric Cancers and treats them as distinct cancer cases different from adult cancers.

Why;

We all know that research and innovation are market-driven, and that means these patients are lagging as innovative therapies and new drugs are not designed for this age group.

Pediatric cancers cannot be prevented.

The toxicity of treatments and drugs in pediatric cancers is extreme. Children face long-term effects of these treatments for most of their lives, with the immediate consequence being their low quality of life.

These are the main reasons why we are asking for the following to be included in the European Cancer Action Plan:

- Equal access to standard-of-care medicines, access to innovative treatments and technology across Europe
- Easy access to innovative drugs and the development of research and technological environment that will develop new drugs designed for young patients
- Funding for pediatric cancer research
- Provide long-term medical care to childhood cancer survivors to improve their quality of life
- Establishment of a European database for pediatric cancers (genome, clinical research, imaging) and use of Artificial Intelligence (AI) to analyze and process data and facilitate research
- Psychosocial and Financial protection of the foster families of these children

Adolescents and young adults are a unique, distinct group of patients. It is not the focus of pediatric oncology research or adult oncology research. Their needs are specific and require special provisions from the European Action Plan against Cancer.

Greece demands together with the European Organizations for Cancer in Children and Adolescents the improvement of the quality of life of all children and adolescents and young adults with cancer and joins the European Agencies to achieve ZERO deaths from cancer for our children.



Professor Pamela Kearns

President of SIOPE (The European Society for Pediatric Oncology)



I am talking to you as the President of the European Society for Paediatric Oncology (SIOPE), and I want to say a big thank you to Maria Spyraiki who is an MEP and a great champion of childhood cancer.

I really appreciated the supportive statements that she made at a recent Gold September Webinar event that was organised by the MEPs Against Cancer (MAC Group).

And I am equally delighted to be talking to you at this important event, which has been organised by Maria Spyraiki and the National Kapodistrian University of Athens and the Association of paediatric doctors of Greece. It is a real honour to have this invitation.

The European Society for Paediatric Oncology is a single united society for health care professionals and is looking after children and young people with cancer. And in Greece, the Hellenic Society of Paediatric Haematology and Oncology, chaired by Professor Kattamis, is our close friend and partner.

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We are working in a close partnership between parents, patients, and survivors, and we have a memorandum of understanding with CCI Europe – the European patients and parents organisation which includes amongst others Karkinaki, founded by Menia Koukougiani.

We also have a memorandum of understanding to work in close partnership with the survivors' organisation called PanCare and together we represent the needs of children and adolescents with cancer throughout Europe.

Just to remind you, paediatric cancers remain a major health and socio-economic burden in Europe. It remains the first cause of death by disease in children over the age of one.

Every year, 35,000 children are diagnosed with cancer in Europe, and more than 6,000 young people die of cancer each year.

For the survivors, at least 60% of the survivors experience a long-term side effect that impacts on how they lead their daily lives. So, there is a lot of work still to be done. At the top, and a theme throughout is inequality:

- There remains unacceptable inequality in access to the best available multidisciplinary care for children with cancer.
- There remains a 20% difference in survival from West to East across Europe.
- There remains a lack of equality in terms of access to therapeutic innovation.

Most of the drugs that we use to treat young people and children with cancer are old drugs, which have been around for many decades and were originally developed for treating adult cancers.

In an era when multiple new targeted therapies are being developed for adult cancers, this is still lacking for childhood cancer. In the last decade, over 150 drugs were developed and licensed for adult cancers, and in that same period, only nine new medicines were licensed for children with cancer.

So, we need early access to early phase clinical trials to develop new drugs for our children.

The other under-served population are the survivors: half a million survivors of paediatric cancer in Europe today, and growing. And yet there remains a lack of organisation in the surveillance for long-term side effects and for long-term follow-up of these patients.

Today is the 30th of September, and it is the final day of the Childhood Cancer Awareness Month. We must be aware of childhood cancer throughout the year, but the initiatives that have gone on in the 'Shine Gold' campaign throughout Europe in support of all children with cancer have been astounding. I am also aware that the Greek Parliament was lit up in gold as a real commitment from your government to the importance of childhood cancer.

So, I congratulate you on organising this exciting event, and I really look forward to working with all of you and with all our colleagues in Greece to champion the specific needs of children and adolescents with cancer in Greece and in the rest of Europe.

Thank you.

Fani Athanasiadou – Piperopoulou

Emeritus Professor of Pediatric Hematology – Oncology AUTH



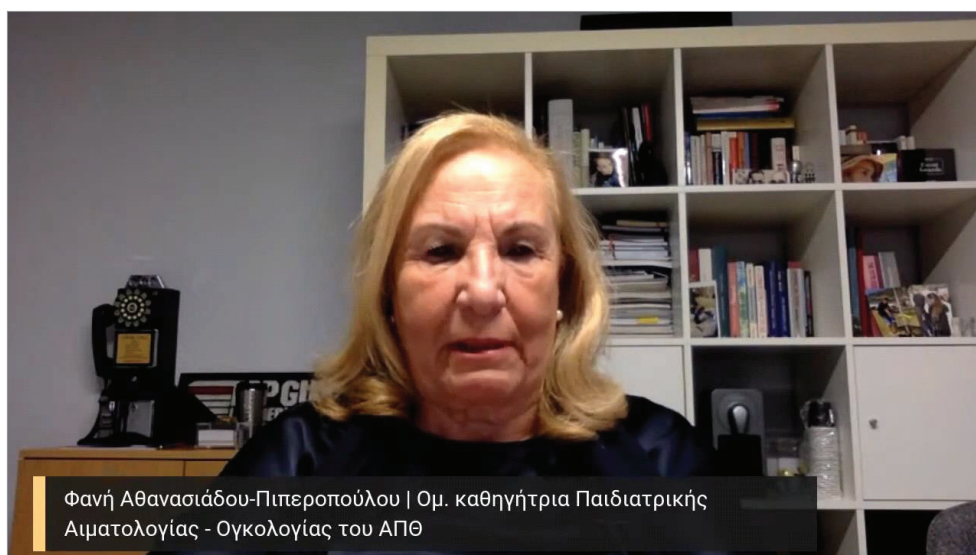
Childhood cancer is still a significant cause of childhood mortality and morbidity in children. It is the second leading cause of death after traffic accidents and a continually rising public health issue worldwide.

The prognosis of neoplastic diseases in children and adolescents has improved during the last 20 years with a survival rate fluctuating from 65-75% for all types of cancer, while for the acute lymphoblastic leukemia (ALL), it exceeds the 80%. Their treatment in the five Pediatric Oncology Departments from Pediatricians specialized in Pediatric Oncology, special nursing personnel, and standard treatment protocols contributed to this progress. Early diagnosis is undoubtedly a crucial factor in the outcome of the disease.

This requires the:

1. Adequate information sharing and awareness-raising to parents for suspicious signs and symptoms that contribute to childhood cancer development.
2. Adequate knowledge of the Pediatrician for the immediate referral of young patients to the the Pediatric Oncology Department and
3. Permanent overnight duties of the 5 Pediatric Oncology Departments that function in Greece.

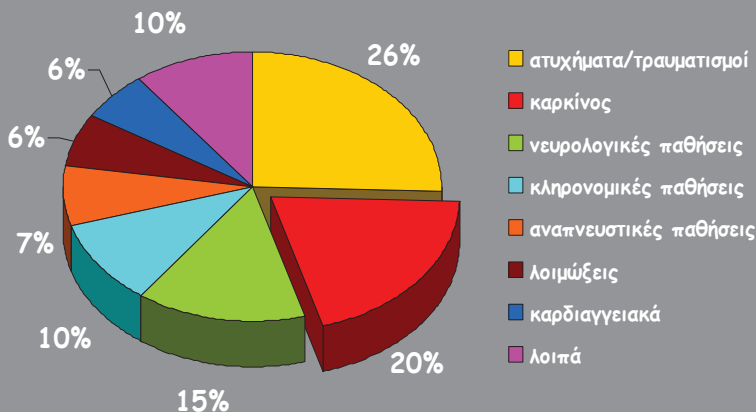
As the challenge to win the battle against cancer is constant, we must all mobilize State – Authorities and Healthcare Workers to submit our proposals to contribute to improving healthcare treatment and the final prognosis of children. **We should always keep in mind that the best prevention of cancer in children is early diagnosis.**



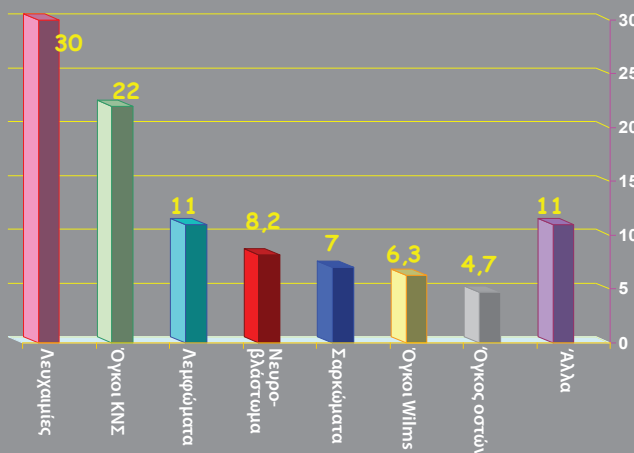
Γιατί είναι σημαντικός ο παιδικός καρκίνος;

- Σημαντικό αίτιο θνητότητας/νοσηρότητας της παιδικής ηλικίας
- Η επιτυχής θεραπεία συμβάλλει σε σημαντική αύξηση της ολικής επιβίωσης
- Η αύξηση της επιβίωσης σχετίζεται με απώτερες επιπλοκές
- Προσφέρεται για βασική έρευνα καθόσον γενετικοί μηχανισμοί ενέχονται στην παθογένειά του
- Αποτελεί αυξανόμενο πρόβλημα της δημόσιας υγείας παγκοσμίως

Θνητότητα από τον καρκίνο στα παιδιά



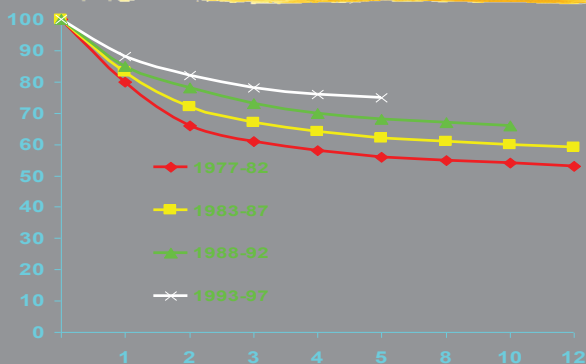
Συχνότητα κακοηθειών παιδικής ηλικίας



Κρίσιμος παράγοντας για την έκβαση της νόσου είναι η έγκαιρη διάγνωση

- Επαρκή ενημέρωση των γονέων για τα ύποπτα σημεία και συμπτώματα με τα οποία εκδηλώνεται ο καρκίνος στα παιδιά
- Επαρκή γνώση του παιδίατρο για την άμεση παραπομπή των μικρών ασθενών σε Παιδοογκολογικό Κέντρο
- Μόνιμη εφημερία των 5 Παιδοογκολογικών Κλινικών που λειτουργούν στη χώρα μας

5ετής Ελεύθερη Νόσου Επιβίωση (Event Free Survival) του παιδικού καρκίνου





Antonis Kattamis

*Professor of EKPA Pediatric Hematology – Oncology Department
President of the Hellenic Society of Pediatric Hematology –
Oncology Department*



Childhood and adolescent cancer is, unfortunately, a reality. Fourteen children and twenty adolescents per 100,000 population will develop cancer each year.

In recent years, the Pediatric Oncology Department has demonstrated significant victories in the fight against cancer. Survival and healing expectancy in most types of cancer has improved significantly. These successes have been based on the close cooperation of pediatricians through working groups and international multicenter studies.

New paths for cancer treatment are opening and are expected to improve the outcomes while significantly avoiding toxicity and possible complications.

Personalized treatment or precision medicine is now an affordable approach. With extensive genetic analysis, significant progress has been made in understanding the pathogenetic mechanisms of cancer. Analysis of the genetic background of cancer cells allows accurate diagnosis of the tumor, correct classification of patients at risk of relapse, and targeted therapeutic approaches. Advances in immunotherapy, that is, the use of immune mechanisms to destroy cancer cells, make it an essential weapon in anti-cancer therapy. The targets of the treatments are usually antigens that are primarily expressed by cancer cells. Specific antibodies have been developed against these targets, leading to the destruction of cancer cells.

Newer approaches focus on binding antibodies to venom molecules or the use of dual-specific antibodies that bring cancer cells and the cytotoxic T-lymphocytes of the immune system into contact. The development of therapies that block the mechanisms of avoiding the immune surveillance of cancer cells leads to the immune system's activation against cancer. Genetically modified T-lymphocytes carrying chimeric antigen receptor (-CAR) receptors against cancer antigens have led to the cure of end-stage patients.

In Greece, there are seven organized pediatric oncology units. The Oncology Center 'Elpida - Marianna V. Vardinogianni' at the General Children's Hospital 'Agia Sofia' hosts the three general oncology units of Athens and the bone marrow transplant unit and treats most of the patients of the Territory. All centers in Greece have excellent cooperation with each other under the auspices of the Hellenic Society of Pediatric Hematology-Oncology (EPAO), which is the exclusive scientific body for doctors working in the field. EPAO and Greek doctors actively participate in the actions and working groups of the European Society for Pediatric Oncology (SIOP-E).

The immediate goals of EPAO are the reorganization of the patient register and the development of coordination structures for non-subsidized academic clinical trials throughout the country. Assistants of the actions and EPAO and all the Units are the associations of Parents and support of children with cancer, such as "FLOGA", "ELPIDA", "PISTI", "LAMPSI", "ILIAHTIDA", "KARKINAKI", etc.

The level of service provision in Greece is particularly high, as shown by the treatments' results and the equal acceptance of the Greek centers in the international treatment protocols. The state must stand next to the health workers of the area and address the system's gaps and imperfections. With advances in science and the support of the State and Society, the goal of curing most patients without long-term complications is achievable in the near future.



Η ΜΑΧΗ ΠΟΥ ΜΠΟΡΟΥΜΕ ΝΑ ΚΕΡΔΙΣΟΥΜΕ

MEPs

Η ΑΝΟΙΞΗ ΤΗΣ ΑΝΟΣΟΘΕΡΑΠΕΙΑΣ

2016 ASCO Advance of the Year

2011: Ipilimumab introduced for melanoma

2014: Pembrolizumab, nivolumab approved for melanoma

2015-2016: PD-1/L-1 drugs benefit even more of cancers

Head/Neck Cancer, Melanoma, Lung Cancer, Kidney Cancer, Bladder Cancer, Hodgkin Lymphoma (Lymph Node Cancer)

Αντώνης Καττάμης

Διοργάνωση: epp ΕΥΡΩΠΑΪΚΟ ΚΟΙΝΩΝΙΚΟ ΠΑΡΤΥ ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ Εθνικισμός και Κοινωνική Δικαιοσύνη Πανεπιστήμιο Αθηνών

ΕΠΙΤΕΥΓΜΑΤΑ ΚΑΙ ΣΤΟΧΟΙ ΣΤΗΝ ΑΝΤΙΜΕΤΩΠΙΣΗ ΤΟΥ ΚΑΡΚΙΝΟΥ ΤΗΣ ΠΑΙΔΙΚΗΣ ΗΛΙΚΙΑΣ

Αντώνης Κατάμης

Καθηγητής Ε.Κ.Π.Α. Παιδιατρικής Αιματολογίας-Ογκολογίας

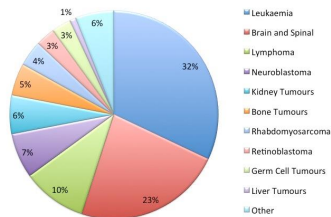
Πρόεδρος Ελληνικής Εταιρείας Παιδιατρικής Αιματολογίας-Ογκολογίας



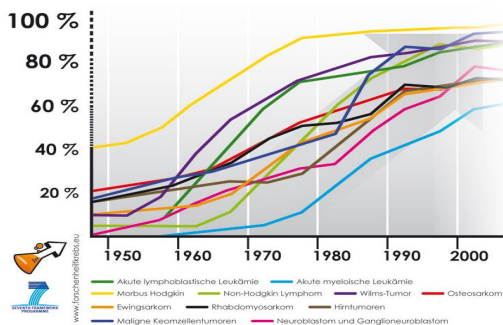
ΚΑΙ ΟΜΩΣ... ΚΑΙ ΤΑ ΠΑΙΔΙΑ ΠΑΘΑΙΝΟΥΝ ΚΑΡΚΙΝΟ

- 14 παιδιά ηλικίας 0- 15 ανά 100.000 παιδικού πληθυσμού και
- 20 έφηβοι ανά 100.000 πληθυσμού ηλικίας 15 έως 18 χρόνων
- 300-350 νέες περιπτώσεις / έτος

Distribution of Childhood Cancer



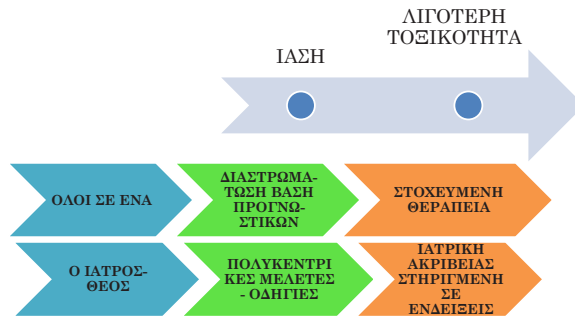
ΠΡΑΓΜΑΤΙΚΟ SUCCESS STORY



From the German Cancer Registry

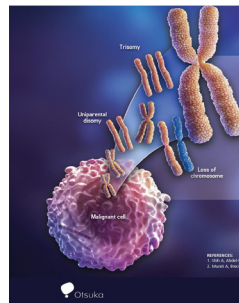


ΔΙΑΧΡΟΝΙΚΗ ΕΞΕΛΙΞΗ ΘΕΡΑΠΕΙΩΝ



Η ΘΕΡΑΠΕΙΑ ΑΛΛΑΖΕΙ

- ΠΟΛΥΚΕΝΤΡΙΚΕΣ ΜΕΛΕΤΕΣ
- ΓΟΝΙΔΙΩΜΑΤΙΚΗ ΤΟΥ ΚΑΡΚΙΝΟΥ
- ΣΤΟΧΕΥΜΕΝΗ ΘΕΡΑΠΕΙΑ
- ΑΝΟΣΟΘΕΡΑΠΕΙΑ



ΓΟΝΙΔΙΩΜΑΤΙΚΗ ΤΟΥ ΚΑΡΚΙΝΟΥ

- Πρωτοστατεί στην εφαρμογή 'Ιατρική Ακρίβειας'
- Η βιολογία του καρκίνου είναι πολύ πιο πολύπλοκη από τις αρχικές προβλέψεις





GENETIC MAP OF CHILDHOOD ALL

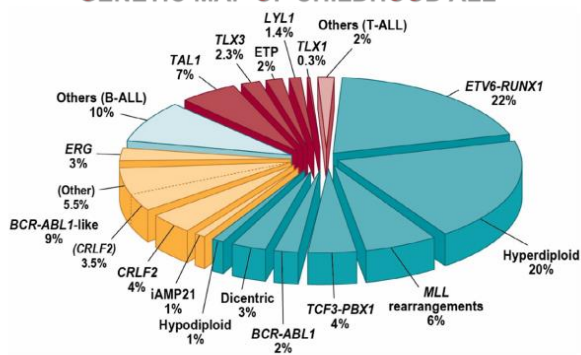
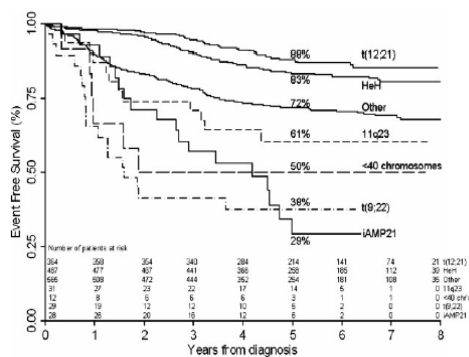


Figure 1.
Subclassification of childhood ALL. Blue wedges refer to B-progenitor ALL, yellow to recently identified subtypes of B-ALL, and red wedges to T-lineage ALL.

Hunger S, Mullighan CG. N Engl J Med 2015; 373:1541-



Ετερογένεια → Πρόγνωση → Θεραπεία



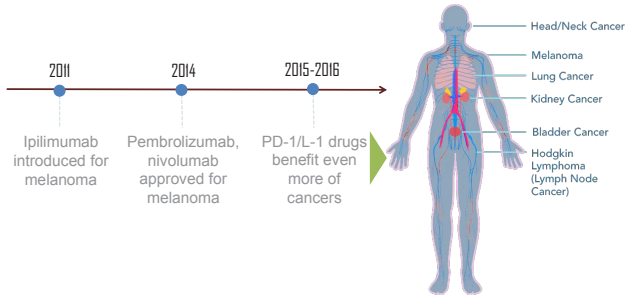
*Moorman AV et al., J Clin Oncol 2013





Η ΑΝΟΙΞΗ ΤΗΣ ΑΝΟΣΟΘΕΡΑΠΕΙΑΣ

2016 ASCO
Advance of the Year



BLINATUMOMAB

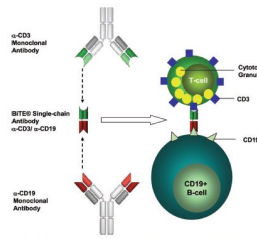


Figure 1. Single-chain antibody Blinatumomab redirects CD3+ T cells to kill CD19+ B cells.

- Bi-specific T-cell engaging (BiTE) antibody that links CD3+ T-cells to CD19+ cells, enabling killing of the CD19+ cells by the patient's own cytotoxic T-cells

Given by continuous 28-day infusion

Side effect profile very different from cytotoxic chemotherapy

- Causes lymphopenia but no significant anemia, thrombocytopenia or neutropenia
- Very low incidence of serious infections
- Unique CNS toxicities including hallucinations and seizures



CHECK POINT INHIBITORS

- T-cell exhaustion
- Programmed death-1 (PD-1)
 - Cytotoxic T-lymphocyte associated protein 4 (CTLA4)
 - Cell lymphocyte activation gene-3 (LAG-3)

- Cancer Cells
- PD-ligand 1

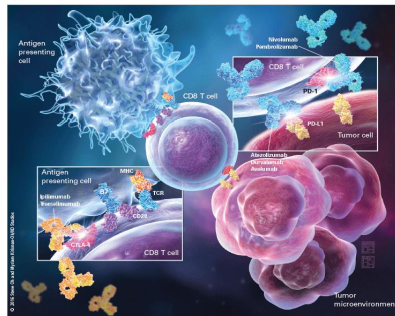
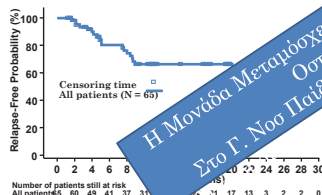


Figure 9. Immune Checkpoint Inhibition Mechanisms of Action Relevant to Lung Cancer Immunotherapy – T cells



OUTCOMES OF CAR T CELL FOR R/R ALL

Tisagenlecleucel



Grupp, ASH 2018



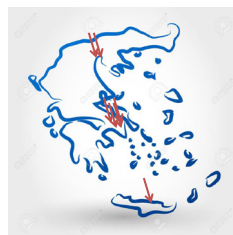
Emily Whitehead –CHOP longest survivor

Η Μονάδα Μεταμόσχευσης Μυελού των Οστών
Στο Γ. Νοσ Παιδών 'Η Αγία Σοφία'



ΠΟΥ ΑΝΤΙΜΕΤΩΠΙΖΟΝΤΑΙ

- Νομικό Πλαίσιο: <16 ετών
- 7 Μονάδες
- 1 Μονάδα Μεταμόσχευσης Μυελού των Οστών
- 2-3 Συνεργαζόμενες Κλινικές



Η ΠΑΙΔΙΑΤΡΙΚΗ ΟΓΚΟΛΟΓΙΑ ΣΤΗΝ ΕΛΛΑΔΑ: ΒΗΜΑΤΑ ΠΡΟΟΔΟΥ

- 2010: Εγκαίνια του Ογκολογικού Κέντρου 'Ελπίδα-Μ.Βαρδινογιάννη'
- Γ.Ν.Παιδών. 'Η Αγία Σοφία'
- 70-80% ασθενών της επικράτειας
- 3 Μονάδες
- 1 ΜΜΟ
- Τμήμα Πυρηνικής Ιατρικής / PET
- 27.830 νοσηλείες στα νοσηλευτικά τμήματα
- 128.320 στις Μονάδες Ημερήσιας Νοσηλείας





ΠΑΝΕΠΙΣΤΗΜΙΑΚΗ ΑΙΜΑΤΟΛΟΓΙΚΗ ΟΓΚΟΛΟΓΙΚΗ ΜΟΝΑΔΑ (Π.Ο.ΑΙ.Μ / ΚΕΘ)

- Μεγαλύτερη Μονάδα στην Επικράτεια
- 2019: 115 ασθενείς
 - >70% των όγκων ΚΝΣ
- Συνεργασία με διεθνή κέντρα
 - DKFZ-Heidelberg
 - CHOP- Philadelphia
- Συμμετοχή σε διεθνείς μελέτες
 - Σε πολλές, ως εθνικός συντονιστής
- Συμμετοχή σε κλινικές μελέτες
 - Φάση 1- φάση 4
- Ερευνητική δραστηριότητα
 - Εξειδικευμένο Εργαστήριο



ΚΟΙΝΗ ΑΙΤΗΣΗ ΤΩΝ 2 ΤΜΗΜΑΤΩΝ Γ. Ν. ΠΑΙΔΩΝ «Η ΑΓΙΑ ΣΟΦΙΑ»: ΠΑΝΕΠΙΣΤΗΜΙΑΚΗ ΜΟΝΑΔΑ – ΤΜΗΜΑ ΑΙΜΑΤΟΛΟΓΙΑΣ-ΟΓΚΟΛΟΓΙΑΣ

ΚΕΝΤΡΟ ΕΜΠΕΙΡΟΓΝΩΜΟΣΥΝΗΣ ΣΠΑΝΙΩΝ ΚΑΙ ΠΟΛΥΠΛΟΚΩΝ ΝΟΣΗΜΑΤΩΝ ΚΑΡΚΙΝΟΥ ΠΑΙΔΙΚΗΣ ΗΛΙΚΙΑΣ PAEDCAN

Συν-υπεύθυνοι:

• Αντώνης Καττάμης

Καθηγητής Παιδιατρικής Αιματολογίας-Ογκολογίας

Υπεύθυνος Πανεπιστημιακής Αιματολογικής Ογκολογικής Μονάδας, Α' Παιδιατρικής Κλινικής ΕΚΠΑ, Γ.Ν. Παιδων «Η Αγία Σοφία»

• Σοφία Πολυχρονοπούλου

Διευθύντρια- Συντονίστρια

Τμήμα Αιματολογίας Ογκολογίας, Γ.Ν. Παιδων «Η Αγία Σοφία»



ΕΛΛΗΝΙΚΗ ΕΤΑΙΡΕΙΑ ΠΑΙΔΙΑΤΡΙΚΗΣ ΑΙΜΑΤΟΛΟΓΙΑΣ-ΟΓΚΟΛΟΓΙΑΣ - ΕΕΠΑΟ

- ΕΕΠΑΟ
 - Από το 1986
 - Αποκλειστικός επιστημονικός φορέας
 - Ευρεία / στενή συνεργασία μεταξύ των μελών
- Διεθνής αναγνώριση και Εκπροσώπηση και συμμετοχή σε ομάδες εργασίες SIOP-E
- Συμμετοχή σε ακαδημαϊκές μελέτες





ΕΛΛΗΝΙΚΗ ΕΤΑΙΡΕΙΑ ΠΑΙΔΙΑΤΡΙΚΗΣ ΑΙΜΑΤΟΛΟΓΙΑΣ-ΟΓΚΟΛΟΓΙΑΣ - ΕΕΠΑΟ

- Συνεργασία με την Πολυτεία σε πολλαπλά επίπεδα
- Εθνικό Μητρώο



ΔΙΕΘΝΕΙΣ ΑΚΑΔΗΜΑΪΚΕΣ ΚΛΙΝΙΚΕΣ ΜΕΛΕΤΕΣ

- Πρόσβαση σε πρωτοποριακές διαγνωστικές μεθόδους και θεραπείες
- Συμμετοχή στην παραγωγή γνώσης που βελτιώνει την αποτελεσματικότητα των θεραπειών
- Άμεση επικοινωνία με μεγάλο δίκτυο διεθνώς για αντιμετώπιση δύσκολων περιστατικών και της ελληνικής ιατρικής
- Αναγνώριση του υψηλού επιπέδου της ελληνικής ιατρικής
- Βελτίωση της οργάνωσης της θεραπείας σε επίπεδο χώρας και επίπεδο μονάδας
- Εξασφάλιση παρόντιδας σε όλα τα κέντρα της Ελλάδας

Βελτίωση του νομικού πλαισίου
Επιχορήγηση της προσπάθειας



ΑΙΤΗΜΑΤΑ ΠΡΟΣ ΤΗΝ ΠΟΛΙΤΕΙΑ

- Δυνατότητα αντιμετώπισης και εφήβων και νεαρών ενηλίκων
- Θέσεις ΕΞΕΙΔΙΚΕΥΜΕΝΟΥ προσωπικού
 - Τμήματα λειτουργούν με Ακαδημαϊκούς Υποτρόφους
 - Ανάγκη αλλαγής μοριοδότησης για εξειδικευμένες θέσεις
 - Νοσηλευτικό και υποστηρικτικό προσωπικό
 - Έμφαση στη ψυχοκοινωνική υπηρεσία
- Αναγνώριση Εξειδίκευση Παιδιατρικής Αιματολογίας-Ογκολογίας
- Ανάπτυξη Εξειδικευμένων Κέντρων για τις πολύπλοκες ογκολογικές επεμβάσεις
- Κέντρο/α Αριστείας και Έρευνας για το Καρκίνο της Παιδικής Ηλικίας
 - Αναφοράς για μοριακές αναλύσεις
 - Κάλυψη εξόδων αναλωσίμων για μοριακές αναλύσεις
- Επιχορήγηση στοχευμένης έρευνας



ΕΚΠΡΟΣΩΠΩΝΤΑΣ ΌΛΟΥΣ ΤΟΥΣ ΛΕΙΤΟΥΡΓΟΥΣ ΥΓΕΙΑΣ ΣΤΟ ΧΩΡΟ ΜΑΣ

ΔΙΑΒΕΒΑΙΩΝΟΥΜΕ

- ΘΕΡΑΠΕΙΑ ΑΝΤΙΣΤΟΙΧΗ ΜΕ ΚΕΝΤΡΑ ΤΟΥ ΕΞΩΤΕΡΙΚΟΥ
- ΑΠΟΤΕΛΕΣΜΑΤΑ ΠΑΡΟΜΟΙΑ
- ΠΡΟΣΒΑΣΗ ΣΕ ΝΕΩΤΕΡΑ ΦΑΡΜΑΚΑ
- ΣΚΟΠΟΣ : ΙΑΣΗ !!!!!



Πανεπιστημιακή Ογκολογική Αιματολογική Μονάδα (Π.Ο.Αι.Μ. / ΚΕΘ) Α' Παιδιατρική Κλινική Ιατρικής Σχολής ΕΚΠΑ



**Π.Ο.Αι.Μ.
ΙΑΤΡΙΚΗ ΟΜΑΔΑ**
Κατάκης Α.
Αυγερινού Γ.
Βλάχου Τ.
Κατσιμπάρδη Κ.
Ρηγίου Ε.
Ρόκα Κ.
Τουρκαντόνη Ν.
Τσίπου Χ.
Φιλιππίδου Μ (DKFZ)
Βιολόγος-Γενετιστής
Σ.Γαλντής



**Υποστήριξη από
Συλλόγους:**
• 'Ελπίδα'
• 'Φλόγα'
• 'Πίστη'
• 'Καρκινάκι'

**ΟΜΑΔΑ ΨΥΧΟΚΟΙΝΩΝΙΚΗΣ
ΥΠΟΣΤΗΡΙΞΗΣ**
Μαρκαντώνη Μαρία
Παφίλη Γαέλι

ΕΥΧΑΡΙΣΤΙΕΣ:
Ασθενείς & τις οικογένειές τους

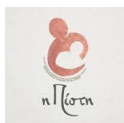


Athens Comprehensive Cancer Center (ACCC) Network



ΑΝΕΚΤΙΜΗΤΟΣ Ο ΡΟΛΟΣ ΤΩΝ ΟΜΑΔΩΝ/ΣΥΛΛΟΓΩΝ ΥΠΟΣΤΗΡΙΞΗΣ

- ΕΛΠΙΔΑ
- ΗΛΙΑΧΤΙΔΑ
- ΚΑΡΚΙΝΑΚΙ
- ΔΑΜΨΗ
- ΠΙΣΤΗ
- ΦΛΟΓΑ
- BE MY HERO
-



ΕΛΠΙΔΑ
ΣΥΛΛΟΓΟΣ ΦΙΛΩΝ ΠΑΙΔΙΩΝ ΜΕ ΚΑΡΚΙΝΟ



Emmanouil S. Hatzipantelis

Associate Professor of Paediatrics & Paediatric Haematology – Oncology at the Aristotle University of Thessaloniki. Head of Children and Adolescent Haematology – Oncology Unit, 2nd Paediatric Department of Aristotle University of Thessaloniki, “AHEPA” University General Hospital of Thessaloniki



ADDRESSING CANCER IN ADOLESCENTS

Adolescence

By the term adolescence, we mean the evolutionary process in human life that begins biologically with the gradual appearance of puberty and ends psychosocially and emotionally with the acquisition of self and gender identity, the acquisition of cognitive function, and the coveted independence. In contrast with the onset of adolescence, which is biologically explicit, its duration is sometimes different, sometimes very prolonged, and depends on idiosyncratic factors, social trends, and cultural parameters. Therefore, the World Health Organization (WHO) considers adolescence the period between 10-19 years, to encompass cultural and transnational differences, while the European Union officially refers to adolescence from the age of 10 to 18 years.

Cancer in adolescents and young adults

Adolescents and young adults (AYAs) are considered the oldest patients in pediatric hematology-oncology, or, as the youngest patients by pathologists hematologists - oncologists. Currently, there are no internationally accepted age limits because health services vary from country to country. The frequency of cancer in adolescence (15-19 years) is about 200 cases per one million population, a rate similar to the ages 0-4 years, but higher than the ages 5-9 years and 10-14 years. The types of cancer that appears in adolescence differ significantly in terms of their frequency at younger ages or in adults. The most common malignancies in adolescence are Hodgkin's disease (16.1%), gonadal tumors (GCT) (15.2%), brain tumors (10%), Non-Hodgkin's lymphoma (7.6%), thyroid cancer (7.2%), malignant melanoma (7%) and Acute Lymphoblastic Leukemia (ALL) (6.4%).

The overall 5-year survival of adolescents with cancer has significantly improved from year to year. For some types of cancer, such as Hodgkin's disease, gonadal tumors (GCT), thyroid cancer, and melanoma, survival rates now exceed 90%. For other types of cancer, such as osteosarcoma, Ewing's sarcoma, ALL, and AML, survival rates in adolescents improved but remained below 60%. More young people of all ages are surviving today than they did in the past, according to a recent publication in the journal Lancet Oncology (EUROCORE-5). Still, AYAs are less likely to survive than young children with eight different cancers (especially leukemias and non - Hodgkin's lymphoma). Also, from this study, it was shown that AYAs had an advantage in survival compared to adults in most cancers (except breast cancer and prostate).

Addressing cancer in adolescents

Adolescents with cancer have been described as the "lost tribe" in terms of their treatment. It is a fact that their participation in clinical research is clearly lower compared to children and older adults. Therefore, they have not benefited as much as they could from the progress that was achieved in the treatment and survival of children and adults with cancer in the last 20 years. It appears that this does not stem only from the problems that are caused by the provision of health services, the delay in diagnosis, but also from the different biology of cancer in adolescents. Most adolescents aged 15-19 are treated in adult groups, despite most types of cancer being similar to those in childhood. Probably the best option would be treated based on the type of tumor and not on age. There is unequivocal literature evidence for some types of cancer, such as leukemias and lymphomas,

based on which treatment with the most intensive pediatric treatment protocols leads to better results.

Concerning tumors that often occur at these ages, such as osteosarcoma and Ewing sarcoma, their biology sometimes resembles that of children and sometimes adults. Their therapeutic approach remains until today a challenge. Previous reports have demonstrated that treating these tumors in pediatric wards with more intensive protocols has led to better survival rates. Nevertheless, the most recent reports have shown that with the implementation of a common treatment protocol (EICESS 92), pediatric and pathology departments' outcomes were similar. These complex and intensive chemotherapeutic regimens and possible surgeries with all their consequences render the treatment for adolescents very hard to tolerate. Thus, it is very important always to consider all the parameters that will help the adolescent fully comply with the treatment and the potential of supporting the administration of the most acceptable remedy.

Adolescents that have survived childhood cancer

Before 1970, almost all children with cancer died of the disease. Today, after leaps and bounds in the progress of the treatment and supportive treatment of the child with cancer, the overall survival is estimated to be more than 80%. That is translated to more than 300,000 childhood cancer survivors in the United States and proportional numbers in the rest of Western countries. As these numbers continue to rise, so does the percentage of children/adolescents/adults monitored predominantly by primary healthcare workers.

Cancer and its treatment could result in a number of organic and psychological complications, which lead to increased morbidity and mortality compared to the general population. Two out of three survivors of childhood cancer will have at least one outer complication associated with treatment. In one to four, this complication will be grave or life-threatening. For these reasons, the well-organized and long-term monitoring of these individuals is required to be diagnosed timely and properly address the ultimate complications of previous cancer treatment. Because these complications are specific and related to the patient's age and type of treatment, monitoring, and laboratory testing should be individualized and based on individual history. The Pediatric Oncology Team of the Children's Oncology Group (COG) in the USA has issued specific guidelines for monitoring children, adolescents, and young adults who have survived childhood cancer to assist patients doctors, especially pediatricians, in providing appropriate health care services.

The smooth transition from Pediatrics to Adult Health Services poses additional difficulties in the treatment for those cured of childhood cancer, as their age increases beyond the pediatric limits of the health system. Proper planning before the transition is an essential step in achieving this goal. The operation of the Medical House model provides a strong structure for this design, which should define the distinct roles of the patient, family, special doctors, and primary healthcare physicians to achieve a smooth transition. For the surviving AYAs, it is important to be fully aware of the potential health problems they will face in the future when they leave the pediatric treatment and be provided with a coherent medical plan for their long-term monitoring. Finally, they should have the knowledge and skills needed to keep them informed, as new information and knowledge will continuously emerge.

Quality of life for adolescent and young adult patients of cancer

Adolescent and young adult cancer survivors face many unique and different challenges and long-term effects that affect their quality of life after the end of treatment. Because of the continuous developments in technology and cancer treatment that have resulted in a significant increase in survival rates, the identification of outer complications and monitoring the quality of life of these patients are particularly important tools of current and future research. According to a recent literature review, AYA childhood cancer survivors were more likely to have a “worse” or “affected” quality of life than the general population, regardless of other demographic factors. The AYAs describe both positive and negative experiences from the healthcare system, their information, and other supportive services. Until today there is no clear data in the literature regarding the interventions that need to take place to improve the quality of life of AYAs. Besides, the tools used for the proper assessment of the quality of life in this population are not satisfactory. However, the literature systematically records this population’s unique needs, demonstrating a trend in health care systems to determine age limits and stages. There is a need to create unique programs for AYAs in the structures of health systems that approach in an interdisciplinary manner the “special” problems of AYAs and aim to improve their quality of life.

Epilogue

The special health needs of adolescents have been recognized by the US and Australian health services since the 1980s, while significant efforts are being made in some European countries (England, Sweden, Italy, Portugal). In the USA and Australia adolescent centers are operating and providing a wide range of clinical health services, while implementing adolescent-specific programs. In addition, many hospitals host operating adolescent healthcare departments. Similar efforts have begun in Greece for some years now.

According to the WHO, the state of health of adolescents in European countries is not satisfactory. This has high social and economic costs and human resources losses. Investing in the improvement of the health of young people inhibits future complications and consists of a real benefit for the whole population—the WHO urges all European countries to prioritize the health of adolescents.

In our country, adolescents constitute 11% of the population (1,300,000 adolescents), and their absolute number displays a diachronic decrease (in 1982, adolescents constituted 14% of the population). As it is known in our country, the older population is constantly increasing, and the current generation of adolescents is called to support them in the future. It is then clear that devotion and contribution to adolescents is an investment - not an unjustified cost.

Selective Bibliography

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Διοργάνωση:



ΑΝΤΙΜΕΤΩΠΙΣΗ ΤΩΝ ΕΦΗΒΩΝ ΜΕ ΚΑΡΚΙΝΟ

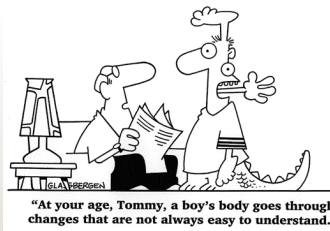
Εμμανουήλ Σ. Χατζηπαντελής,
Αναπληρωτής Καθηγητής Παιδιατρικής & Παιδιατρικής Αιματολογίας -Ογκολογίας Α.Π.Θ.,
Μονάδα Παιδικής & Εφηβικής Αιματολογίας - Ογκολογίας Β' Παιδιατρικής Κλινικής Α.Π.Θ.,
ΑΧΕΠΑ Π.Γ.Ν.Θ.

I state no conflict of interest

ΕΦΗΒΕΙΑ

- Σε αντίθεση με την έναρξή της, που είναι βιολογικά σαφής, η **διάρκεια** της είναι άλλοτε άλλη, καμιά φορά πολύ παρατεταμένη και εξαρτάται από ιδιοσυγκρασιακούς παράγοντες, κοινωνικές τάσεις και πολιτισμικές παραμέτρους.
- Η Παγκόσμια Οργάνωση Υγείας θεωρεί **εφηβεία** το διάστημα από 10-19 ετών προκειμένου να περιλάβει πολιτισμικές και διακρατικές διαφορές, ενώ η Ευρωπαϊκή Ένωση επισήμως αναφέρεται στην εφηβεία από την ηλικία των 10 έως 18 ετών.

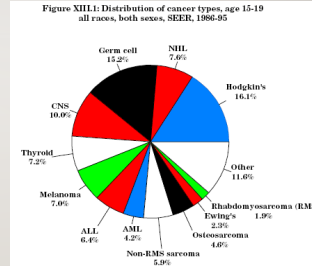
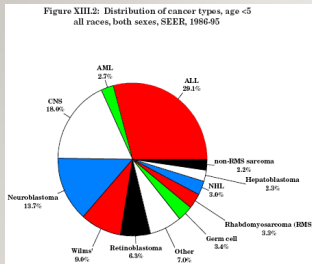
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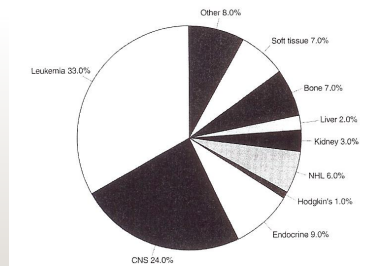
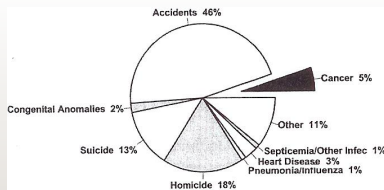
Καρκίνος στους εφήβους και νεαρούς ενήλικες: ηλικιακά όρια

- AYA are usually considered as the older patients in pediatric oncology or hematology practice and the younger patients in adult practice.
- At present, there are no universally accepted limits that define the age range because the interface between adult and children's services is different in different healthcare systems.
- WHO definition: 10-14 years: pre-adolescent; 15-19 years: adolescent; 20-24 years: post-adolescent .
- Teenage years are between 13 and 19 years of age, inclusive. Older patients, 20-39 years of age, are generally considered as "young adults".

Συχνότητα ιστολογικών τύπων καρκίνου παιδιών <5 ετών και εφήβων >15 ετών



Κυριότερες αιτίες θανάτου στους εφήβους



Survival of European adolescents and young adults diagnosed with cancer in 2000-07: population-based data from EUROcare-5.

Annalisa Trama, Laura Botta, Roberto Foschi, Andrea Ferrari, Charles Stiller, Emmanuel Desandes, Milena Maria Maule, Franco Merletti, Gemma Gatta.
The Lancet Oncology, 2016;

More young people of all ages are surviving cancer than ever before, but new research published in *The Lancet Oncology* journal shows that adolescents and young adults have a lower chance of surviving eight relatively common types of cancer than children, according to the latest data from a long-running study of cancer survival across Europe.

The authors say that variations in survival between age groups are due to a number of factors including: delays in diagnosis and treatment, a lack of treatment guidelines and clinical trials specifically for teenagers and young adults, as well as differences in the biology of some cancers.

"However," "we found that adolescents and young adults still tend to die earlier than children for several cancers common to these age groups, particularly blood cancers like leukemias and non-Hodgkin's lymphoma (NHL)."

The latest EUROCare-5 report includes, for the first time, comparison of survival between adolescents and young adults (aged 15-39 years), children (aged 0-14 years) and adults (aged 40-69 years), who were diagnosed from 2000 to 2007, and followed-up to at least 2008. The researchers analysed data from population-based cancer registries covering all or part of 27 European countries, and estimated 5-year survival for 56505 cancer cases in children, 312483 in adolescents and young adults, and 3567383 in adults. They also analysed changes in survival over time from 1999 to 2007.

- For adolescents and young adults, survival at 5 years from diagnosis for all cancers combined is generally good with 82% now surviving (2005-07) up from 79% in 1999-2001, in children survival improved from 76% to 79% over the same period.

Adolescents and young adults had a survival advantage over adults for almost all major cancers affecting both age groups, supporting the idea that younger patients with few other illnesses are likely to fare better than older patients.

There are only two types of cancer for which adolescents and young adults were at a survival disadvantage -- breast (83.5% vs 87.0%) and prostate (79.9% vs 89.8%). This reflects the fact that younger women often present with larger, higher-grade cancers that are more advanced, and that prostate disease tends to be more aggressive in younger men.

Αντιμετώπιση του εφήβου και νέου ενήλικα με καρκίνο. Η καλύτερη θεραπευτική προσέγγιση.

Οι έφηβοι με καρκίνο έχουν περιγραφεί ως η «χαμένη φυλή» (the lost tribe), σε ότι αφορά τη θεραπευτική τους αντιμετώπιση. Είναι γεγονός ότι η συμμετοχή τους σε κλινικές μελέτες είναι σαφώς μικρότερη σε σχέση με τα παιδιά και τους μεγαλύτερους ενήλικες και συνεπώς δεν έχουν ωφεληθεί όσο θα μπορούσαν από τις προόδους που επιτεύχθηκαν στην αντιμετώπιση και την επιβίωση των παιδιών και ενηλίκων με καρκίνο τα τελευταία 20 χρόνια.

Φαίνεται ότι αυτό δεν οφείλεται μόνο στα προβλήματα που αντιμετωπίζουν από τις παρεχόμενες υπηρεσίες υγείας, καθυστέρηση στη διάγνωση, αλλά και στη διαφορετική βιολογία του καρκίνου στους εφήβους. Οι περισσότεροι από τους εφήβους 15-19 ετών αντιμετωπίζονται σε τμήματα ενηλίκων, παρ'ότι η πλειονότητα των μορφών καρκίνου που εμφανίζουν προσομοιάζει με αυτούς της παιδικής ηλικίας.

Πιθανώς η καλύτερη επιλογή θα ήταν η θεραπευτική αντιμετώπιση με βάση τον τύπο του όγκου και όχι με βάση την ηλικία.

Για μερικές μορφές καρκίνου, όπως οι λευχαιμίες και τα λεμφώματα, υπάρχουν σαφή βιβλιογραφικά δεδομένα, με βάση τα οποία η αντιμετώπιση με τα πιο εντατικά θεραπευτικά παιδιατρικά πρωτόκολλα οδηγεί σε καλύτερα αποτελέσματα. Όσον αφορά τους όγκους που εμφανίζονται συχνότερα στις ηλικίες αυτές, όπως είναι το οστεοσάρκωμα και το σάρκωμα Ewing, η βιολογία τους άλλοτε προσμοιάζει με αυτή των παιδιών και άλλοτε με αυτή των ενηλίκων. Η θεραπευτική τους προσέγγιση αποτελεί έως σήμερα μία πρόκληση. Παλαιότερες αναφορές έδειξαν ότι η αντιμετώπιση των όγκων αυτών σε παιδιατρικά τμήματα με πιο εντατικά πρωτόκολλα οδήγησαν σε καλύτερα ποσοστά επιβίωσης. **Παρ' όλα αυτά, οι πιο πρόσφατες αναφορές έδειξαν ότι με την εφαρμογή κοινού θεραπευτικού πρωτοκόλλου (EICESS 92) τα αποτελέσματα στα παιδιατρικά και στα παθολογικά τμήματα ήταν παρόμοια.**

Τα πολύπλοκα και εντατικά χημειοθεραπευτικά αυτά σχήματα, καθώς και οι πιθανές χειρουργικές επεμβάσεις με όλες τις συνέπειές τους, καθιστούν τη θεραπεία πολύ δύσκολα ανεκτή από τους εφήβους. Για το λόγο αυτό, έχει μεγάλη σημασία να εξετάζονται πάντοτε όλες οι παράμετροι που θα βοηθήσουν στην πλήρη συμμόρφωση του εφήβου με τη θεραπεία, καθώς και οι δυνατότητες υποστήριξης της χορήγησης της καλύτερα αποδεκτής θεραπείας.

Patient Related Outcome Measures 2015:6 19–51
<http://dx.doi.org/10.2147/PROM.S51658>

Quality of life in adolescent and young adult cancer patients: a systematic review of the literature

Gwendolyn P Quinn, Vnia Goncalves, Ivana Sehic, Meghan L Bowman, Damon R Reed
 H Lee Moffitt Cancer Center and Research Institute, Department of Health Outcomes and Behavior, Tampa, FL, USA; Morsani College of Medicine, University of South Florida, Tampa, FL, USA; H Lee Moffitt Cancer Center and Research Institute, Adolescent Young Adult Oncology Program, Tampa, FL, USA; Faculty of Psychology and Educational Sciences, University of Coimbra, Coimbra, Portugal; H Lee Moffitt Cancer Center and Research Institute, Department of Sarcoma, Tampa, FL, USA

Introduction: Adolescent and young adult (AYA) cancer survivors experience many unique challenges and quality of life (QoL) effects that persist beyond cancer diagnosis and treatment. Due to continuous improvements in technology and cancer treatments resulting in improved survival rates, the identification of late effects, survivorship issues, and QoL is moving to the forefront of cancer research. The goal of this systematic review was to identify key psychosocial factors impacting QoL in AYA oncology populations.

Methods: A systematic review of the literature was conducted using combinations of these phrases or keywords: “adolescent and young adult or AYA” AND “health outcomes OR quality of life OR psychology” AND “neoplasm OR cancer OR oncology”. A total of 35 articles were included in this review. Studies were classified into two categories: AYA perceptions and stakeholder perceptions.

Results: AYA cancer survivors were more likely to have “worse” or impaired QoL compared with the general population, regardless of other demographic factors. AYAs described both positive and negatives experiences with their medical care, the educational information received, and the supportive care services. Although health care professionals were likely to underestimate or misjudge the health preferences and support needs of AYAs, these perceptions varied across disciplines and levels of experience.

Conclusion: The literature is lacking in sufficient evidence-based interventions to improve QoL in AYA cancer populations. Further, the tools to adequately measure QoL in this population are also unsatisfactory. The literature, however, consistently shows agreement regarding the unique needs of this population, indicating a trend toward health care standardization within age ranges or life stages. **We suggest the need for AYA-specific programs in health care institutions that comprise a multidisciplinary team that addresses all the unique medical and QoL needs of AYAs.**



Επίλογος

Σύμφωνα με την Π.Ο.Υ. η κατάσταση της υγείας των εφήβων στις Ευρωπαϊκές χώρες δεν είναι ικανοποιητική. Αυτό έχει σημαντικό κοινωνικό και οικονομικό κόστος και απώλειες σε ανθρώπινο δυναμικό. Η επένδυση στη βελτίωση της υγείας των νεαρών ατόμων αναστέλλει τις επιπλοκές του μέλλοντος και αποτελεί πραγματικό κέρδος για το σύνολο του πληθυσμού. Ο Π.Ο.Υ. προτρέπει όλες τις Ευρωπαϊκές χώρες να δώσουν προτεραιότητα στην υγεία της εφηβικής ηλικίας.

Στη χώρα μας οι έφηβοι αποτελούν το 11% του πληθυσμού (1.300.000 έφηβοι) και ο απόλυτος αριθμός τους παρουσιάζει διαχρονική μείωση (το 1982 οι έφηβοι αποτελούσαν το 14% του πληθυσμού). Όπως είναι γνωστό για τη χώρα μας, ο γηραιότερος πληθυσμός συνεχώς αυξάνεται και η γενιά των τωρινών εφήβων καλείται να τους στηρίξει στο μέλλον.

Είναι, λοιπόν, σαφές πως η αφοσίωση και η προσφορά στους εφήβους είναι μία επένδυση - όχι ένα αδικαιολόγητο κόστος.

Katerina Katsibardi, MD, PhD

*Pediatrician, Academic Fellow at the Pediatric Hematology Oncology Unit,
1st Department of Pediatrics, Aghia Sophia Children's Hospital, National
and Kapodistrian University of Athens.*



Late effects in childhood cancer survivors

50

Significant progress has been noted concerning the survival of children with cancer during the last decades, since the 5-year event free survival nowadays reaches 80%, even exceeding that in specific types of childhood malignancies. Therefore, currently childhood cancer survivors account 500,000 in Europe and 400,000 in USA. During 2020, it was estimated that one in 350 adults had a history of cancer in childhood and it seems that this population is constantly increasing due to the success in their treatment.

However, “being cancer free is not the same as being free of cancer”. Therefore, all childhood cancer survivors have regular follow up, in order to monitor if they

remain in disease remission and to identify probable relapse, but also to detect as early as possible, complications, which may occur either prompt or delayed, 2 to 5 years, after cancer treatment completion.

Late effects in childhood cancer survivors are a result of chemotherapy, particularly of high doses of alkylating agents, but they are also a consequence of radiotherapy, surgery especially in patients with brain tumors or bone marrow transplantation.

Approximately the 75% of childhood cancer survivors will present at least one complication, while the 25% of them will have a very serious or a life-threatening condition during their lifetime. Additionally, survivors display health problems much earlier compared to the general population and specifically during the period of 35-50 years old. For instance, the risk of obesity at young age is two times higher, 14%, compared to the general population, which is 7.5%. The risk of death due to cardiovascular disease, even at a young age, is seven times higher in childhood cancer survivors. The incidence of early ovarian failure is ten times higher in adult women that received antineoplastic treatment in their childhood, than in the general population, 8% versus 0.8%.

The most common complications that survivors may experience are endocrine disorders (hypothyroidism, short stature, early or late puberty), cardiovascular disease and metabolic syndrome or obesity. They may also present bone disorders (osteopenia or osteoporosis), hearing impairment and neurocognitive disorders, with adverse effect on their performance at school. In addition, childhood cancer survivors may experience reproductive disorders, manifested as menstrual disorders, erectile dysfunction, premature menopause and infertility.

The effect of chemotherapy and abdominal radiation on the gonads is dismal and can lead a woman who survived childhood cancer to menopause before the age of 40 years old and in some cases even before the age of 25 years old, with final effect on fertility.

The occurrence of late effects has negative influence on the quality of life of survivors, either it concerns the period of childhood with an impact on their school and social reintegration, or their lives as adults, by influencing their relationships, their work and their social identity.

Early detection of potential complications and their treatment approach is significant in order to achieve a better quality of life in childhood cancer survivors. Late effects clinics for monitoring childhood cancer survivors is an essential compartment of all pediatric oncology departments.

The interdisciplinary approach and collaboration with adult groups are two important elements in better addressing the subsequent late effects of childhood cancer survivors.



Διοργάνωση:



ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ
Εθνικόν και Καποδιστριακόν
Πανεπιστήμιον Αθηνών

Η ΜΑΧΗ ΠΟΥ ΜΠΟΡΟΥΜΕ ΝΑ ΚΕΡΔΙΣΟΥΜΕ

MEPs
EUROPEAN PARLIAMENT

Ηλικία εμφάνισης επιπλοκών

- 95%: χρόνια ή απειλητική για τη ζωή κατάσταση (<45 ετών)
- 2/3: σοβαρές (<35 ετών) ή απειλητικές για τη ζωή επιπλοκές (<50 ετών)

- Πρώιμη ηλικία σε σύγκριση με γενικό πληθυσμό
- Αύξηση επιπλοκών με την πάροδο της ηλικίας

Armstrong et al. J Clin Oncol. 2014;32:1218-27

Διοργάνωση:



ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ
Εθνικόν και Καποδιστριακόν
Πανεπιστήμιον Αθηνών

Η επόμενη ημέρα μετά την ολοκλήρωση της αντινεοπλασματικής θεραπείας



Κατερίνα Κατσιμπάρδη

Παιδίατρος, Ακαδημαϊκός Υπότροφος
Πανεπιστημιακή Ογκολογική - Αιματολογική Μονάδα

Α' Παιδιατρική Κλινική ΕΚΠΑ
Γ.Ν. Παίδων Αθηνών «Η Αγία Σοφία»



"Being cancer-free is not the same as being free of cancer"

Managing
late effects for
pediatric
cancer survivors.



400,000 pediatric cancer survivors in the United States.

73%
will have a
chronic health
condition.

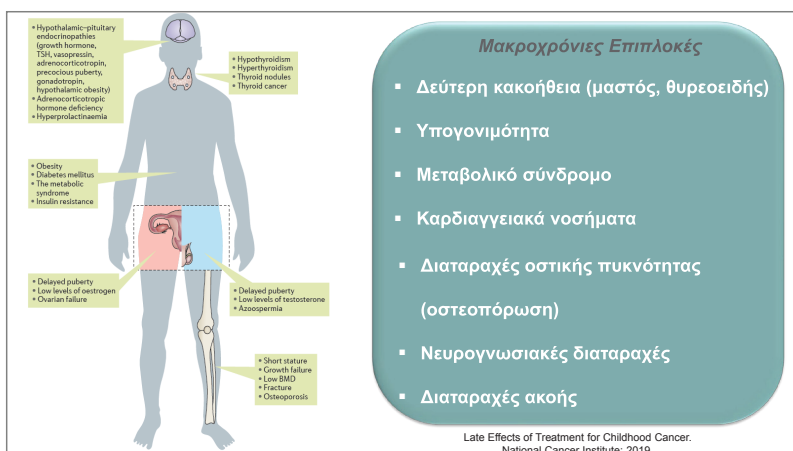
42%
of those will likely experience
severe, disabling or life-
threatening condition or death.

Vassal et al., 2016; Howard et al., 2018.

Επιβιώσαντες

- 500.000 επιβιώσαντες (Ευρώπη)
- 400.000 επιβιώσαντες (ΗΠΑ)
- 1.300 άτομα αύξηση / ετησίως

**2020: 1 στους 350 ενήλικες
έχει ιστορικό καρκίνου
στην παιδική ηλικία**

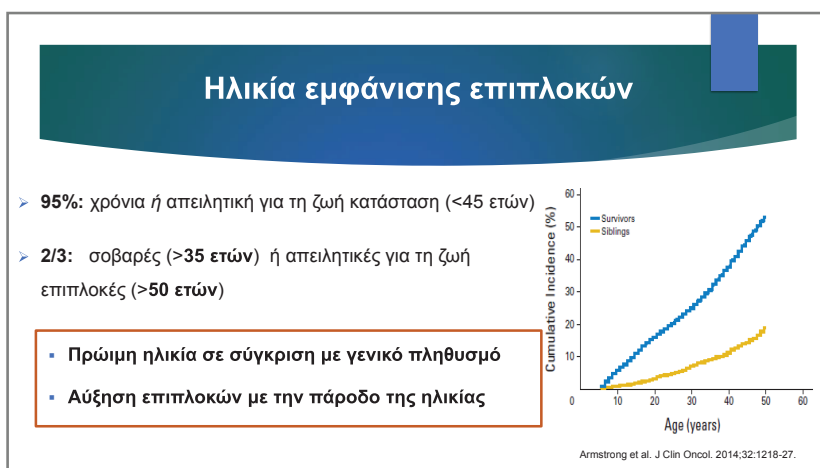
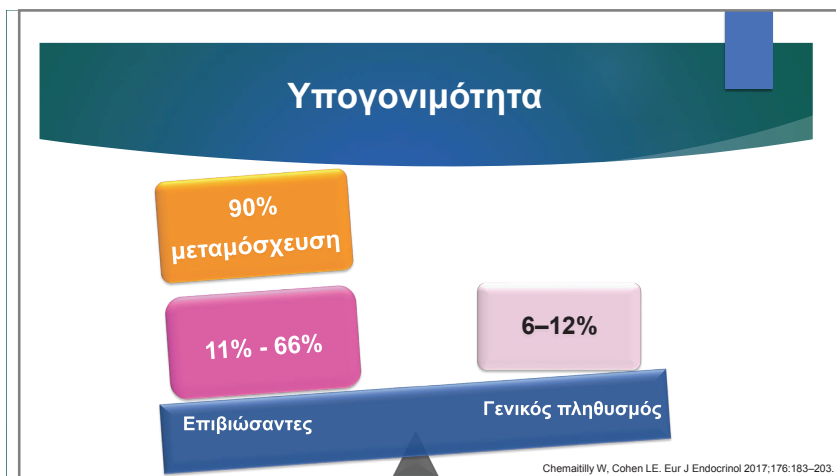


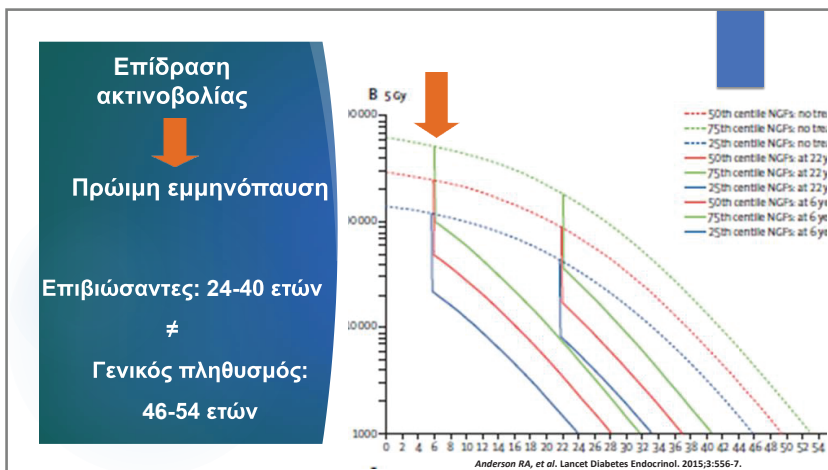
Μακροχρόνιες Επιπλοκές: αυξημένος κίνδυνος νοσηρότητας

5 έτη
μετά το πέρας
της θεραπείας

- 3:4 επιβιώσαντες ➡ τουλάχιστον μια επιπλοκή
- 1:4 επιβιώσαντες ➡ απειλητική κατάσταση για τη ζωή
- 14% : παχυσαρκία σε νεαρή ηλικία (7,5% σύγκριση με γενικό πληθυσμό)
- 7 X : θάνατος από καρδιαγγειακά νοσήματα
- 8% : πρόωγη ωθηκική ανεπάρκεια (0,8% σύγκριση με γενικό πληθυσμό)

St. Jude's Lifetime Cohort of childhood cancer survivors. J Clin Oncol 2014;32:1218-27.





Ποιότητα ζωής (quality of life)

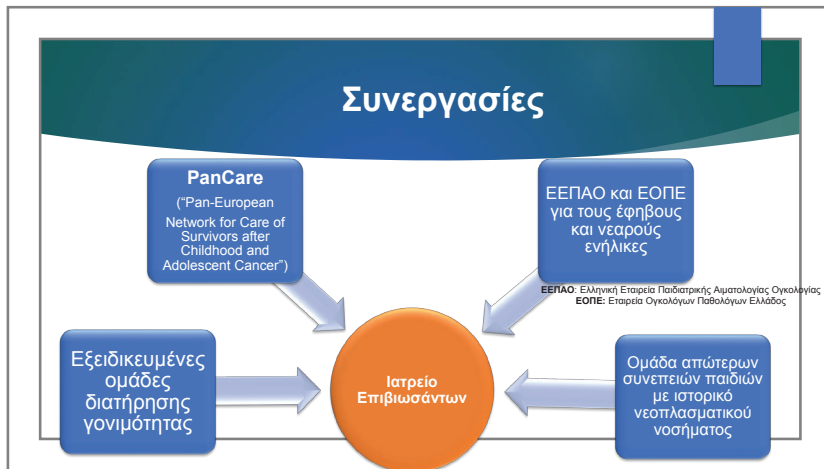
- Ψυχολογική υποστήριξη (μετατραυματικό stress, αγχώδης συνδρομή, κατάθλιψη)
- Ένταση στο σχολείο, εργασία, κοινωνικό σύνολο
- Τεκνοποίηση

Human reproduction ORIGINAL ARTICLE Infertility

‘Will I be able to have a baby?’ Results from online focus group discussions with childhood cancer survivors in Sweden

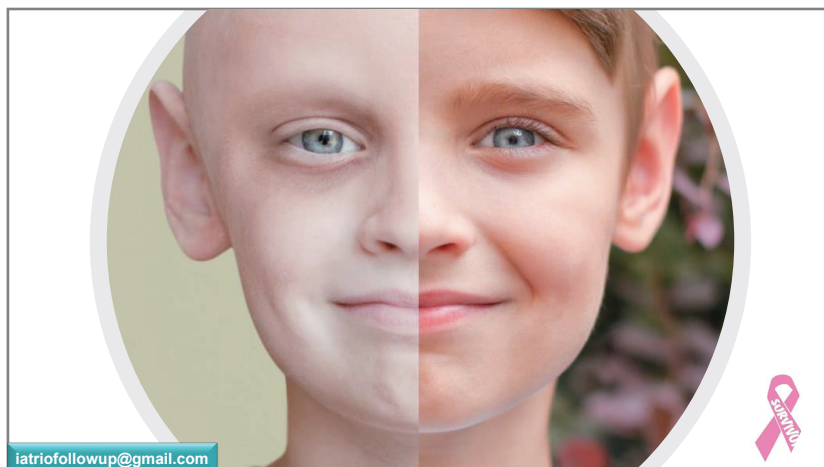
Ομαδική προσέγγιση

- ΠΑΙΔΙΑΤΡΟΣ
- ΟΓΚΟΛΟΓΟΣ - ΑΙΜΑΤΟΛΟΓΟΣ
- ΑΚΤΙΝΟΘΕΡΑΠΕΥΤΗΣ - ΑΚΤΙΝΟΛΟΓΟΣ
- ΕΝΔΟΚΡΙΝΟΛΟΓΟΣ - ΓΥΝΑΙΚΟΛΟΓΟΣ
- ΚΑΡΔΙΟΛΟΓΟΣ
- ΠΑΘΟΛΟΓΟΣ - ΓΕΝΙΚΟΣ ΙΑΤΡΟΣ
- ΨΥΧΟΛΟΓΟΣ- ΔΙΑΙΤΟΛΟΓΟΣ- ΚΟΙΝΩΝΙΚΗ ΛΕΙΤΟΥΡΓΟΣ- ΓΕΝΕΤΙΣΤΗΣ



Η επόμενη ημέρα ...

- Ενημέρωση - έγκαιρη ανίχνευση - αντιμετώπιση μακροχρόνιων επιπλοκών
- Διασφάλιση ποιότητας ζωής
- ❖ Διεπιστημονική προσέγγιση και συνεργασία



Rapti Zoi

Deputy Minister of Health



Thank you very much for inviting me to participate in this event-driven by the **Childhood and Adolescence Cancer Awareness Month**.

In particular, I would like to thank:

- **Ms. Maria Spyraiki, Member of the European Parliament**, for initiating today's open webinar discussion-briefing, which establishes the foundation for the outset of a dialogue on combatting childhood and adolescent cancer.
- **Ms. Marianna Vardinogiannis**, UNESCO Goodwill Ambassador and President of ELPIDA "Association of Friends of Children with Cancer."
- **Ms. Anastasia Stamatea**, President of Association "Pisti" - Association for parents-children with cancer.
- **Ms. Menia Koukougiani**, Co-Founder of the NGO "KAPKINAKI" and Member of the Research and Innovation Group of Childhood Cancer International (CCI) Europe.

- **Mr. Athanasios Exadaktylos**, Chairman of Panhellenic Medical Association.
- **Mr. Thanos Dimopoulos**, Rector of the National and Kapodistrian University of Athens.
- **Professor Pamela Kearns**, President of SIOPE (The European Society for Pediatric Oncology)

and the following Professors:

- **Ms. Fani Athanasiadou – Piperopoulou**, Emeritus Professor of Pediatric Hematology-Oncology in the Aristotle University of Thessaloniki.
- **Mr. Antonis Kattamis**, Professor of Pediatric Hematology-Oncology in the National and Kapodistrian University of Athens and President of EEPAO (Hellenic society of Pediatric Hematology-Oncology).
- **Mr. Emmanouil Chatzipantelis**, Associate Professor of Pediatric Hematology-Oncology in the Aristotle University of Thessaloniki.
- **Ms. Katerina Katsibardi**, Pediatrician, Ph.D. in Medicine in the National and Kapodistrian University of Athens, Resident in Pediatric Hematology-Oncology in the First Department of Pediatrics of NKUA, Aghia Sophia Children's Hospital.

The data from the World Health Organization (WHO) about childhood cancer are shocking:

1. Every year, approximately 250.000 children worldwide are affected by cancer, from which only a 20% percentage acquires access to proper medical treatment.
2. In Europe, 20 children are dying every day from cancer.
3. A percentage of 70%-80% of children who acquire access to special treatment manages to overcome the disease because of medical science's progress and the adequacy in medicaments and qualified scientific personnel.
4. The **improvement of childhood cancer healthcare** constitutes a **priority for the National Health System (ESY)**. Cancer is the second, in terms of frequency, cause of death in children after traffic accidents.
5. In Greece, approximately 300 children are affected every year by cancer, mainly from leukemia. However, 8 out of 10 children that today present leukemia are cured.
6. The State **recognizes the significant contribution of ELPIDA "Association of Friends of Children with Cancer."** It has integrated into National Health System (ESY) the **"Children's Oncology Unit Marianna V. Vardinoyannis-ELPIDA,"** which is a donation from «ELPIDA» and thanks to which Greek children that are affected, have the opportunity to be treated with high scientific standards.

7. **In the battle against cancer, the State will show succor/support both to the children who battle against cancer and their families.** We all know that cancer diagnosis in children or adolescents consists of a massive wound, not only for the child but also for the family, since anything that was taken for granted until that time is overturned. The family's balance and stability are unsettled, setting into crisis even the most stable familial structures.

The Ministry of Health has scheduled :

8. **The Registry of patients with rare types of cancer**, in which childhood cancer is also included.
- a) **The proposal of the Working Group responsible for creating National Registry for Patients with Childhood Cancer has been completed.**
 - b) **The proposal of the Committee for the creation of therapeutic protocols and registries of patients is currently at the stage of issuance of a Ministerial Decision (YA) to start the function of the Register.**
 - c) **In parallel, the digitalization of the Registry of Patients with Childhood Cancer from E-Governance in Social Security (HAIKA) is progressing, being integrated as mandatory in the electronic prescribing system.**

And has advanced:

9. **In the establishment of Therapeutic Prescribing Protocols for leukemia and lymphomas, they have to do with malignant diseases in children and adolescents** and solid neoplasms and hematologic cancer. These protocols have been published on the website of the Ministry of Health.
10. **But the magnitude of challenges and necessities for the children with cancer and their families, which the health system is called to address, is huge.**
11. I will insist a lot on **psychological and psychosocial support and the creation of a comprehensive and regulatory system for the psychological support of the affected children and their families, which lies under my jurisdiction.**
12. During the next months, the Ministry is planning actions that concern:
- a) **The strengthening of interdisciplinary teams of pediatric-oncology clinics (departments) with psychologists and child psychiatrists for the psychological support of children affected and the psychosocial support of their parents.**
 - b) **Awareness programs in mental health issues for treating psychological consequences of childhood cancer of the medical and nursing staff that work in pediatric-oncology hospitals and clinics.**

13. The objective of the State should be to provide along with treatment, **psychological and psychosocial care for the child and the members of the family and the preservation of the quality of life for the child and the members of the family showing respect in the sensitivity and the age of the young warriors.**
14. The **cooperation between authorities and the associations of active parents and the scientific personnel, doctors, and healthcare workers are essential for beating childhood cancer.**
15. Concluding I would like to **highlight, using as a pretext the presence of scientists, professors of our medical schools in universities and the Chairman of the Panhellenic Medical Association, the vital role and contribution of the medical and nursing staff, composed of people of the frontline that give a battle for the rescue of these children and in this regard I would like to say a huge “thank you” to them.**

The fact that today we all together demonstrate that in this battle against childhood cancer, the State, the organizations, the parent’s associations, the medical and nursing staff, we are all allies.



This is a battle that we can win!!!



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