



CREATE **YOUR** FUTURE



# POLICY RECOMENDATIONS



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# Introduction



When taking a close look at Childhood Cancer Organisation across Europe it becomes clear that the offers for children diagnosed with cancer as well as their families and Childhood Cancer Survivors are mostly being financed by private or corporate funds that the Organisations receive. Involvement of the government and its institutions is not only lacking money-wise but also support-wise.

For many decades the focus of Childhood Cancer Organisation was on the timeframe from the diagnose until the end of treatment. Simply because the death rate was much higher than it is now. Nowadays around 80 Percent of all children diagnosed with cancer, resulting in Survivors trying to get back to educational settings and of course later on trying to find a job.

Due to the late effects that two thirds of all Survivors suffer from, finding their way back to education or work contains many challenges. The Childhood Cancer Organisations reacted to this need with support and a well-elaborated project for Childhood Cancer Survivors: individual Career Counselling that is taken into consideration possible late effects. Now, the Childhood Cancer Organisation have come to a point where the support from governmental level is needed. For this reason policy recommendations have been created in the European Project Create your Future to address stakeholders and ministries in order to demand their support to assure the integration of Childhood Cancer Survivors in the labour market.

This document is a summary of the policy recommendations from the countries Austria, Spain, Bulgaria and Greece.

# Policy recommendations



## Austria

In Austria around 300 children and adolescents are being diagnosed with cancer every year. Around 80 Percent survive cancer, this is equivalent to 240 children and adolescents. Of this 240 children and adolescents, two thirds experience suffer from late effects that lead to mayor challenges in the integration of the labour market. So every year 70 survivors emerge, that need support on their way back to education or work. This makes a number of 700 in only 10 years, not counting those survivors that have been treated within the last three decades and not having had any support. In a persons lifetime (the average life expectansy rate of women in Austria is 83,2 years) 5824 Survivors will need support in order to assure a successfull participation in the labour market.

The Austrian Policy Recommendations are addressed to two different Ministries, the Ministry of Health and Women and the Ministry of Labor and Social Policy. Education and Ministry of Labor and Social Policy. The document refers to necessity for change and improvement of the policy and legislation regarding children and youths with cancer and childhood cancer survivors in order to ensure their successful realization as adults in society and in labor market.

- Creating awareness and focusing on overcoming discrimination of Childhood Cancer Survivors in the Labor Market and during the application process by advocating companies and minimizing their fears of employing Childhood Cancer Survivors. This is currently being done by the Austrian Childhood Cancer Organisation and its partners but with a very small reach, it therefore needs a stakeholder on a governmental level to push this topic forward.
- Creating a network of companies and organisations that are informed on Childhood Cancer Issues and are offering internships, apprenticeship and jobs for Childhood Cancer Survivors.
- Encouraging flexibility in educational and work settings regarding working hours and breaks. This is due to the fact that approximately two third of all Childhood Cancer Survivors need to slightly increase their



educational hours or working hours a day as fulltime courses or jobs are not manageable due to late effects. A new routine first has to be implemented by the survivors before being able increase the educational or working hours. This work is also being covered by the Austrian Childhood Cancer Organisation but again, this topic needs to be adressed on a governmental level in order to bring the success that this work deserves to have.

- Creating a system that raises teachers' and vocational trainers' awareness about Childhood Cancer and its late effects in order to enable Childhood Cancer Survivors to go back to school etc without being discriminated. Currently, this awareness raising is being done by the psychologists working in pediatrial clinics in Austria.

## Spain

In Spain, about 1.400 new cases of childhood cancer are diagnosed every year. Childhood cancer is still the main cause of death among children between 0 and 14 years.

The most frequent cancer type is Leukemia (25%), followed by central nervous system (19,6%) and lymphomas (13,6%)<sup>1</sup>. Survival rate is almost 80%, according to Spanish Society of Pediatric Oncology (<http://www.sehop.org>), which is a similar rate of most European countries.

When it comes to teenagers, data is not so clear, as these are not recorded in the Spanish National Childhood Tumors Registration. Most of these cases are treated in Adults cancer units. One of the goals of the Spanish Childhood Cancer associations is to change this situation and achieve that all children up to 18 years are treated in pediatric oncology units or specifically created units for teenagers.

Other demands are aimed at providing more support to their educational needs, highlighting the need of specific



protocols and orientation to teachers to deal with these children/teenagers.

Regarding social demands, there's a need of having a long term psychological support for these patients and their families, as well as job / studies orientation to reintegrate them into society in the best conditions.

This is an emerging social group who has specific needs which we, as society, are not fully aware of. It has made itself visible in the last years, and we still lack of enough studies to fully understand their needs and personal experiences. In this document we provide a summary of the findings from our project in Spain, as well as some recommendations for policies to implement at national level.

## Bulgaria

Bulgarian Recommendations is addressed to Ministry of Education and Ministry of Labor and Social Policy. The document refers to necessity for change and improvement of the policy and legislation regarding children and youths with cancer and childhood cancer survivors in order to ensure their successful realization as adults in society and in labor market.

### **The following suggestions could change the current situation:**

1. Children and adolescents with cancer and childhood cancer survivors to be recognized as children and young people at risk. This will involve decision makers and responsible people and institutions to be more informed and responding adequately and timely at the different stages of treatment and reintegration.
2. Ensure adequate and constant access to quality education during active treatment and maintenance therapy. From January 2017 In Bulgaria all hospital schools are closed and school-age patients have to prepare themselves and take exams, which puts them at a disadvantage compared to their peers. The lack education in



the hospital during treatment also puts them at risk of dropping out of school at least for an year or permanently.

3. Raise the awareness of teachers, peers, state institutions and other stakeholders about the nature of the disease, the risks causes from treatment, and the specific needs of children and adolescents. Since childhood cancer is a rare disease, information about the disease itself, treatment and late effects is insufficient. High awareness helps provide better quality support and adequate care during maintenance therapy and subsequent return to school and restoring normal life routine.

4. Ensure that barriers to labor market implementation are overcome. Some types of tumors require surgery. In these cases, a limb or eye may be removed, brain tumors may cause motor disorders, vestibular disorder. Brain surgery and radiotherapy can lead to temporary or permanent memory disorders, fine motor disorders, rapid tiredness and low concentration. Good practices show that active work in Thies fiel helps to overcome these difficulties and improve the chances of realization in the labor market.

## Greece

In Greece, the childhood cancer and its late-effects are presented in the general framework for the people with disabilities. However, there is no law or regulation which protects or gives equal rights to the survivors or disabled. Most of the politicians ignore this issue or think that it is not extremely important as the percentage of survivors in Greece is very low. In the last decades, the incidents of childhood cancer are more frequent and people have started to worry a lot about the consequences of the therapies and the medicines. Politicians should create a solid policy and a constant campaign in order to inform the public and the employers. In Greece, two ministries which would contribute to this process are the Ministry of Health and the Ministry of Employment and Employability.

In Greece, survivors usually prefer not to mention their health issue to employers or to other people. Childhood cancer is a taboo for the Greek society especially in close communities. The majority of the cases of childhood





cancers are curable and most of the times, their late-effects are almost non existing. However, the self-esteem and the self –confidence is not very high to survivors. They seem afraid that their problem will come back in the future and this makes them less courageous. These characteristics proved from the questionnaires and the mini interviews conducted with survivors in the first stage of the project „Create your Future“

### **Establish a protection framework for children who have passed childhood cancer**

- Protecting the educational process (enhancing teaching)
- Social and psychological support (especially in cases with obvious side effects of the treatment process)
- Establish a percentage of recruitment for workers who have passed childhood cancer.
- Establishment or creation of a parallel technical training section for survivors of childhood cancer.

### **Implementation and next steps**

- 1) Raising awareness campaign for employers and businesses on childhood cancer
- 2) Supporting the educational process of children in hospital or rehabilitation
- 3) Contact with businesses to organize a Career Day or Open Coffee
- 4) Collaboration with businesses and other Non Profit Organizations to organize Career Day for people with disabilities



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