

1 Publishable Summary

DIRECT: EC-funded project to promote the success story of childhood cancer research to the general public

As a direct consequence of funding, in large parts by private foundations as well as by public grants, such as the EC's Framework Programmes, dramatic advances in paediatric cancer research were achieved. Over the past four decades, the 5-year-survival rates have been raised from less than 20% to nearly 80%. This is attributed to the outstanding collaborative work of national and international paediatric cancer groups performing clinical trials as well as to progressive developments in anaesthesia and surgery, supportive care regimens, and the discovery of effective drugs.

It is estimated that there are currently between 300,000 and 500,000 adults in Europe who have survived cancer treated in their childhood or youth¹. As survival rates improve, this number will continuously grow. Although the majority of childhood cancer patients can expect to be cured, there are significant health problems in many survivors, such as coping with orthopaedic or surgical devices like prostheses, growth and fertility impairment due to hormonal disturbances, drug-induced heart or kidney problems or the development of a secondary cancer.

More discrete changes can refer to disturbances of concentration and learning abilities, or in psychological and social adjustment at large. Psychosocial problems, for example to find a job, get a private health insurance and/or life assurance, are not uncommon among European childhood cancer survivors. Stigmatisation and poorer employment prospects due to diffuse social prejudices in our society are commonplace. Most recent research also revealed that many former childhood cancer patients are actually distinguishing themselves through high resilience and a post-traumatic resistance. They dispose over a strong psychological maturity, a lot of compassion and a strong value of life compared to their peers without cancer histories because of their previous difficult experiences.

To illustrate the efficient treatments currently available to European children and adolescents with cancer, pass on hope, trust and courage to young cancer patients being currently under treatment and foster public awareness of the necessities in providing clinical, psychological and psychosocial cure for childhood cancer patients and survivors in future, the DIRECT project team organized two activities in Austria and Germany which both have been given extensive media coverage.

On the 6th September 2009, eight young childhood cancer survivors from Austria, Germany and Poland aged seventeen to thirty-six undertook a five-day adventure to Austria's highest peak. Accompanied by DIRECT project representatives from St. Anna Children's Hospital and Children's Cancer Research Institute, an outdoor psychologist, a professional film team and mountain guides, they overcame all dangers and hurdles, such as ice fields and fixed rope routes, and made it right to the Grossglockner top at 3,798 meters.



The coordinating mountain guide was highly impressed: „These young people display an incredible inner strength, determination and endurance.“ „I am trying to use what I have learned as a result of my cancer in everyday life, such as stamina, perseverance and hopefulness. This way at least I did not go through all this in vain“, explained Lisbeth, the youngest alpinist of the group.

During the eight-day Rainbow tour, the participants – forty childhood cancer survivors – left 600 kilometers behind them as they cycled from Mannheim to Cologne, thereby showing that childhood

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cancer survivors can perform at maximum levels just like their peers without cancer histories and giving hope to those who are still fighting the battle. As a yearly campaign of the German Childhood Cancer Foundation over the last 16 years, the Rainbow Tour's motto is encouragement, information and awareness. The rainbow warriors traditionally stop at children's hospitals to visit young patients and their families on the cancer wards. Their main goal is to demonstrate: "You can make it, just like we did!"



„Dealing with cancer is often characterized by fear, denial and uncertainty. Especially young patients are feeling the effects – be it at school, among friends or later in the professional life. A lot of education is still required in this respect,” explains Jens Kort, managing director of the organization and DIRECT project partner.

Both events were publicly communicated through a coordinated strategy. The key issues were disseminated via the multi-lingual DIRECT website, including amazing pictures, video clips of the five-day climbing tour, audio-visual material of an interview given by a cyclist, and a web-blog set up by cyclists and mountaineers in order to create a clear connection between the EC-funded science communication project DIRECT and the highly motivated young adults who have successfully overcome cancer.

In fact awe-inspiring snapshots and touching entries on the blog written by the participants about their cancer diseases, about physical changes and confrontations with the professional world as former patients resulted from both DIRECT activities. Hence, a high-quality hard cover book entitled “Of Mountaineers and Rainbow Tour Riders” was produced to give confidence and hope to children and adolescents with cancer as well as their families and friends. For stakeholders and deciders, this DIRECT book is designed to provide an orientation guide on past successes and future challenges of paediatric oncology and related research. The book is used by Austrian and German patient organizations and distributed by survivors at paediatric cancer wards. In addition to the book, a 27-minute film was produced presenting all of the five days of the Grossglockner adventure tour.

TV is the medium with the highest impact on the general public. In collaboration with the DIRECT project partner Pammer Film, the team produced a 45-minute tv-documentary entitled “Little heroes – great opportunities. Childhood cancer research in Europe” which combines interviews of paediatric oncologists and scientists from various European childhood cancer centers, affected families, young patients and survivors with the climbing of the Grossglockner peak and the Rainbow Tour. The aim in producing this film was to communicate the strong link between private and public funding of childhood cancer research, which makes improved and new treatment options available and the growing number of European children and teenagers who have overcome cancer. Despite many positive aspects, the film clearly demonstrates the need for continual funding of childhood cancer research and presents current obstacles that have to be overcome scientifically, politically and within our society to reach total cure and care for young patients with cancer.

On 12th August, the tv-documentary will be broadcast at 8.15 pm via 3sat which is available on the European Astra satellites at 19.2° east, cable television, and in Austria and Germany on digital terrestrial television. It can be viewed by 40 million households in Germany, Austria and Switzerland and 85,5 million households in all of Europe.

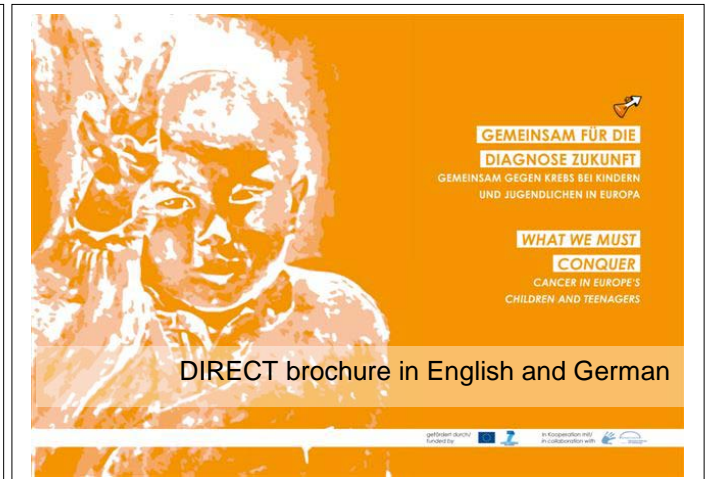
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To complete the DIRECT communication channels, dvds, including an English and German version of the tv documentary, and a detailed brochure entitled “What we must conquer. Cancer in Europe’s children and teenagers” in collaboration with the German Competence Network Paediatric Oncology/Haematology (KPOH) were developed in corporate DIRECT design. These materials are distributed through patient organizations and constitute essential milestones to inform deciders, media representatives and stakeholders on the broad spectrum of paediatric oncology and related research.



Film poster of the DIRECT tv documentary with representation of DIRECT logo and FP7 logo



DIRECT brochure in English and German



DIRECT book on climbing an Alpine peak and the Rainbow Tour

On 28th February, the DIRECT project team presented the tv-documentary “Little heroes – great opportunities. Childhood cancer research in Europe” and the film of the mountaineering tour in a Viennese cinema to 172 invited guests, among them clinicians, childhood cancer survivors, representatives of patient organizations, media representatives, potential sponsors and stakeholders. A very popular Austrian tv-presenter explained the most important issues of the DIRECT project to the audience by interviewing Michael Dworzak, MD, paediatric oncologist at the St. Anna Children’s Hospital, medical coordinator of the Grossglockner tour and DIRECT project partner on stage. The event was “styled” in DIRECT design and was used to distribute the DIRECT print materials. There were film posters hanged up in the cinema’s showcases and foyer, the entrance tickets had DIRECT corporate design. All of the guests received promotion bags which were filled with three DIRECT items: the DIRECT brochure “What we must conquer – Cancer in Europe’s children and adolescents”, the DIRECT book reporting on the mountaineering and the biking tours and the DIRECT dvd of the film “Little heroes – great opportunities”.

The manifold, strategically coordinated communication channels which describe the field of childhood cancer research and its impact on European society have already appealed many different target groups and are developed in a way that they will have a lasting effect, certainly even beyond the project DIRECT.

[1] R. Ladenstein. Paediatric oncology in Europe: current situation and future directions. Memo (2009) Vol. 2: 2-3.

For detailed information, please visit <http://www.overcomingcancerwithresearch.eu>

DIRECT project-partners:

German Childhood Cancer Foundation | www.kinderkrebsstiftung.de

St. Anna Children's Cancer Hospital | www.stanna.at

Otto Pammer Filmproduktion | www.pammerfilm.at

Coordinating organisation

Children's Cancer Research Institute | www.ccri.at

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Images and Graphics of Publishable Summary in higher resolution





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FILMPREMIERE
Sonntag, 28. Februar 2010
Metro Kino, Wien

KLEINE HELDEN GROSSE CHANCEN KINDERKREBSFORSCHUNG IN EUROPA

Buch und Regie: Gustav W. Trampitsch
 Produktion: Pammer Film



gefördert durch:



Projektpartner:








**GEMEINSAM FÜR DIE
DIAGNOSE ZUKUNFT**

GEMEINSAM GEGEN KREBS BEI KINDERN
UND JUGENDLICHEN IN EUROPA

**WHAT WE MUST
CONQUER**

CANCER IN EUROPE'S
CHILDREN AND TEENAGERS

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