

Delicate balance for childhood cancer: Political action in Austria is required. From groundbreaking EC-funded science communication to the current needs and strategic development plans presented by St. Anna's doctors and researchers

“Overcoming Cancer with Research”: the internationally renowned St. Anna Children’s Cancer Research Institute (CCRI) and the project partners German Childhood Cancer Foundation, St. Anna Children’s Hospital (SAN) and Pammerfilm dedicated this message to an almost three-year EC-funded science communication project until the end of October 2010. The Austrian-German team of DIRECT, short for “Disseminate Results from EC funded projects improved Therapy options in paediatric oncology”, applied manifold, strategically coordinated channels of science communication as efficient means to make the public aware of the relationship between the accomplishments of childhood cancer research and the impressively improved overall cure rates in children and adolescents with cancer in Europe over the past four decades. The multilingual web portal, a brochure outlining the benefits of paediatric cancer research for European society, public events on life sciences and specific cancers in children, such as sarcomas, and the TV documentary “Young heroes – great opportunities” which is also available in English on DVD were important steps to sensitise the public with a lasting effect.



First row, on the right: Sarcoma-Awareness-Bike Tour. Interview given by a childhood cancer survivor.
Second row: Students’ & public forum “Understanding Cancer – Saving Lives”; on the right: DIRECT Coordinator Prof. Helmut Gadner and Dr. Susanne Brandsteidl, president of the Vienna School Board

“DIRECT enabled us to develop efficient tools to inform media representatives, stakeholders and the general public about the specific needs of children with cancer and long-term survivors in an effective and sustainable way”, explained project coordinator Prof. Gadner, director of CCRI at the closing press conference of DIRECT. Paediatric oncologists and researchers of CCRI and SAN reported on the positive outcomes of DIRECT to the press. In addition, they also revealed the prevailing gaps and urgent needs in the field of paediatric oncology to reach total cure for every child with any kind of cancer in Europe and ensure the continuity of child-cancer research, in particular in Austria and Germany.

As a direct consequence of funding, in large parts by private donations 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 in young cancer patients have been raised from less than 20% to nearly 80% in industrialized European countries. This is attributed to the

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outstanding collaborative work of national and international networks performing clinical trials as well as to biomedical advances and progressive developments in chemotherapy, radiotherapy and surgery.



On the left: Closing press conference of DIRECT: Eva Frey, MD, senior physician at the haemato-oncological department of SAN, partner of EC-project "PANCARESURFUP"
2nd picture on the left: Assoc. Prof. Heinrich Kovar, PhD, scientific director of CCRI, partner of EC project "ASSET"
In the middle: Assoc. Prof. Ruth Ladenstein, MD, senior physician at SAN, head of CCR's department "Clinical studies and statistics", president of SIOPE, coordinator of EC-project "ENCCA"
On the right: Assoc. Prof. Michael Dworzak, MD, senior physician at SAN, CCRI researcher and partner of project "DIRECT"

In spite of these successes, cancer continues to be the number one lethal disease among children in Europe. More specialised research into the causes and special characteristics of paediatric leukaemia and malignant tumours which differ greatly from cancer in adults in many ways and which are very rare is required.

Greater chances of cure through joint know-how and a strong network

During the international "DIRECT" symposium in Vienna, paediatric oncologists, researchers, patient representatives of parent initiatives, the scientific officer of the EU-department for cancer research and local health authorities as well as childhood cancer survivors compiled strategic development plans to meet the new challenges, such as the need of innovative drugs, children's right of access to standardised cancer treatments, improved legal frameworks for further development of treatment protocols and a uniform Europe-wide concept of aftercare for childhood cancer survivors, in particular for those entering adulthood. They all confirmed the necessity of a stronger sustainable infrastructure for clinical research and a strong joint network of the various European paediatric oncological committees. Major hope is therefore pinned on the four-year EC-funded project "ENCCA" which starts in January 2011. Three scientific articles in the medium "*Magazine of European Medical Oncology – Memo*", Volume 04/09, were published, describing the DIRECT activities, the discussions of the DIRECT symposium and successful EC-funded research projects to promote research into cancers in children.



From the middle to the right: Prof. Gilles Vassal, coordinator of the EC-funded project "KIDSCANCERKINOME" and Prof. Masera, childhood cancer expert from Italy, during the international DIRECT symposium held in May 2008.

Improved treatment in clinical studies thanks to harmonised legal frameworks

Another issue of the international "DIRECT" symposium was to discuss the work-loads and additional requirements caused by the EU Clinical Trials Directive (2001/20/EC) and the EU Paediatric Regulation (1901/2006).

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The inhomogeneous implementation of these regulations in the 27 EU member states make the international collaboration of paediatric cancer specialists difficult. In the aftermath of the symposium, three major suggestions for taking remedial action to solve the issues of off-label drugs for children with cancer were also published in the "Memo Magazine", Volume 04/09. Special reprints on paediatric oncology were disseminated to the participants of this year's I-BFM (international Berlin-Frankfurt-Muenster study group) meeting. The goal is clearly defined: to make the faster use of diagnostic and therapeutic innovations possible in order to warrant even higher cure rates and less side-effects of therapy for all children and adolescents with cancer.

Improved quality of life after overcoming cancer thanks to epidemiological research

Paediatric oncology is faced with a new reality. 300'000 to 500'000 childhood cancer survivors currently reside in Europe as young adults. Society is faced with potential medical long-term effects as well as psychological and psychosocial problems. Intensified research is intended to help understand why some children have a higher risk for adverse therapeutic effects. Epidemiological studies are strongly needed to help prepare and implement uniform follow-up guidelines and an aftercare concept for adult childhood cancer survivors throughout Europe. The "DIRECT" team performed lobbying work for a new EC-funded project "PancareSURFup", which will be conducting relevant analyses. "DIRECT" measures, such as the ascent to Austria's highest peak, Grossglockner at 3.798 altitude meters, or the "Rainbow Tour", a 600 kilometre bike tour through Germany with childhood cancer survivors and a "book of encouragement" for patients and their families detailing these efforts pursue one goal: to back up the acceptance of these young adults as members of our society with equal rights to education, jobs and private, complementary and life insurances.



„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 German Childhood Cancer Foundation and DIRECT project partner.

Better future without gaps

The DIRECT team agrees that their diverse, strategically coordinated measures of science communication have initiated important dialogues with diverse stakeholders and contributed to a better understanding of the complex issues of paediatric oncology and to the acceptance of public funding of childhood cancer research which should be continual and non-competitive. However, detailed dialogues and cooperations with potent partners in politics and the pharmaceutical industry have to be realised to ensure the future developments for the benefit of the diseased children and adolescents with cancer in Europe. A goal which is not just academic, but a societal must: children are our future.

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

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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

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