



International Childhood Cancer Awareness Day (ICCD) 2018

***Paediatric Cancers in Europe – The Road Ahead:
Towards FP9 and the next EU Health Funding Programmes***

20 February 2018, 14:30 – 17:00

European Parliament (ASP 3H1), Brussels, Belgium

Hosted by MEP Elena Gentile (IT, S&D)



Life after childhood cancer – Novel solutions for survivors of childhood cancer

Jaap den Hartogh

PanCare
Dutch Childhood Cancer Parent Organization





“Cure is not enough”

Giulio J. D'Angio MD (1975)



PanCare (2008 -)







Strategic aim of PanCare

To ensure
that every European survivor of
childhood and adolescent cancer
receives optimal long-term care.



Survivorship in Europe

- **Overall 5-year survival rate: 80% in developed countries**
- **Better treatments and supportive care, thanks to research**
- **Estimated 300-500,000 CCS in Europe**
- **Another 10-12,000 new CCS each year**
- **This has a price: late effects of the treatment**
 - **$\frac{2}{3}$ of the CCS has one or more severe late effects**
- **Negative impact on quality of life**



The 'price' that comes with surviving

- **Medical late effects**
 - Organ / system impairment or failure
 - Functional impairment
 - Chronic fatigue
 - Second cancers
- **Psychological late effects**
- **Social late effects**
 - Job opportunities
 - Insurances
 - Mortgages

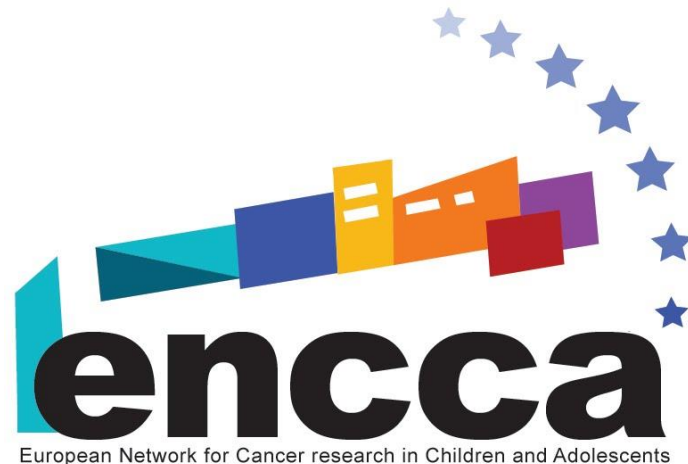


What has been done?

Previous EU Projects on CCS (1)

- **ENCCA: European Network for Cancer research in Children and Adolescents (EU FP7, 2011-2015)**

<https://www.siope.eu/encca/>

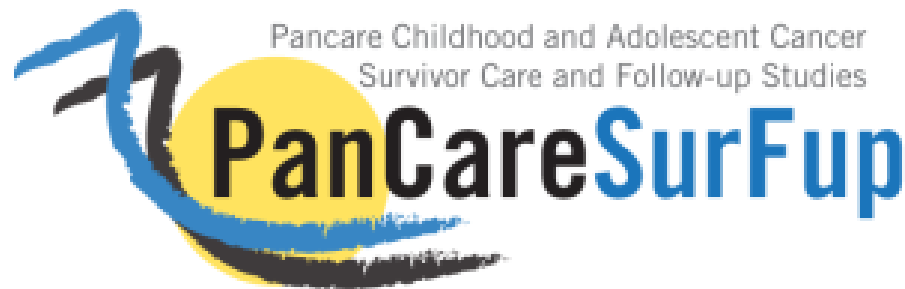




What has been done?

Previous EU Projects on CCS (2)

- **PanCareSurFup: PanCare childhood and adolescent cancer Survivor care and Follow-Up studies (EU FP7, 2011-2017)**
 - <http://www.pancaresurfup.eu/>





What has been done?

Previous EU Projects on CCS (3)

- **ExPO-r-Net: European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment (EU Health Programme, 2013-2017)**
 - <http://www.expornet.eu/>





What has been done?

Previous EU Projects on CCS (4)

- **PanCareLIFE: PanCare studies in fertility and ototoxicity to improve quality of life after cancer during childhood, adolescence and young adulthood (EU FP7, 2013-2018)**
 - <http://www.pancarelife.eu/>





Results

- **Various guidelines**
 - Lancet, Journal of Clinical Oncology
- **Risk factors -- > improve current treatments**
- **Survivorship Passport**
- **ERN PaedCan**



**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Paediatric Cancer
(ERN PaedCan)



What's should be on the research and care agenda? (1)

- **Inequalities regarding care**
 - New type of patients
 - Access between 0% - 100%
 - No long-term follow-up, both children and adults
 - Need for smooth transition between paediatric care and adult care
 - Need for specialized physicians
 - No end-of-treatment summary available
 - Survivor can't take responsibility
 - Guidelines are needed to provide optimal care



What's should be on the research and care agenda? (2)

- **Guideline development**
 - **Aims: to improve long-term health outcomes in CCS**
 - **Necessary to improve care**
 - **Necessary to improve quality of life**
 - **Necessary to complete Survivorship Passport**



What's should be on the research and care agenda? (3)

- **Further development of the Survivorship Passport**
 - Identify barriers of implementation
 - Privacy matters
 - Remaining guidelines
 - Survivors' empowerment



What's should be on the research and care agenda? (4)

- **Social consequences**
 - Education
 - Employment
 - Insurances / mortgages



With the support and commitment of all stakeholders, childhood cancer survivors can be actively engaged in society and live their lives to the fullest.

Thanks for your attention!