The PanCare Network and its EU related projects

ECPC General Assembly
Brussels June 4
Lars Hjorth, MD PhD
Lund Sweden

PEDIATRIC CANCER IN PERSPECTIVE: CURE IS NOT ENOUGH

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Current Perspective

Long term survivors of childhood cancer: Cure and care

The Erice Statement

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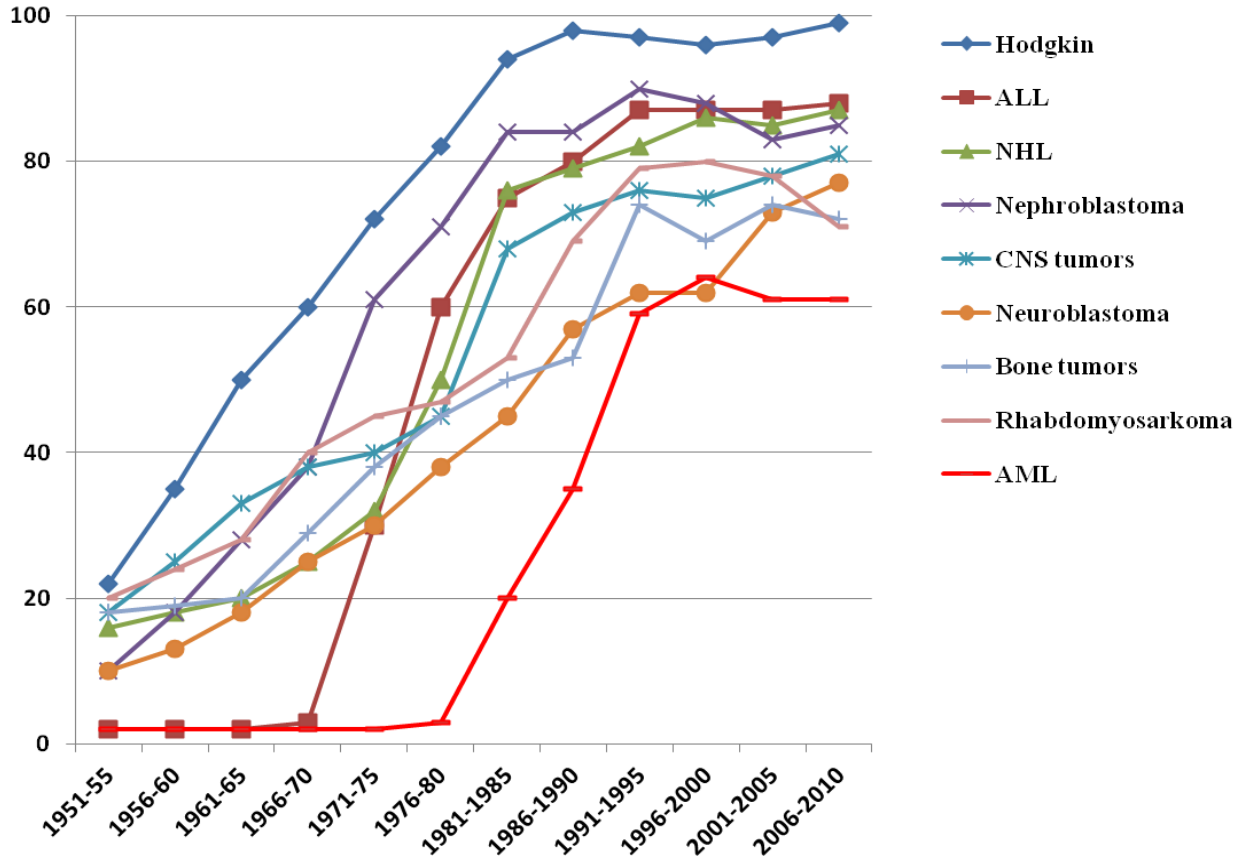
Prognosis over time



Thanks to Mats Heyman, CCEG Stockholm

Background data on childhood cancer

- Up to 80 % five year survival in developed countries
- 15,000 new cases each year in Europe with 12,000 expected to be long-term survivors
- Estimated 300 – 500,000 survivors in Europe
- Around 350,000 CCS in the U.S.
- Estimated number of survivors of childhood cancer in the general population in Europe is 1 in 1,000
- Unlike adult cancer (diagnosis mostly > 60 years of age) survivors of childhood cancer have their whole lives ahead of them
- Therefore, surveillance, diagnosis, treatment and prevention of late complications are critical

Childhood Cancer Survivor Study (CCSS) (North America)

Retrospective cohort study following 10,397 CCS (diagnosed between 1970-1986) and 3,034 siblings:

- Median age 26.6 years (18-48) for CCS
- **62.3%** had at least one chronic condition
- **27.5%** had a severe or life-threatening condition
- RR of a chronic condition was **3.3** for CCS compared to siblings
- RR of a severe or life-threatening condition was **8.2**
- Cumulative incidence of a chronic health condition was **73.4%** 30 years after diagnosis. Cumulative incidence for severe, life-threatening conditions or death was **42.4%**
- **Incidence increases over time and does not appear to plateau!**

Oeffinger et al. Chronic health conditions in adult survivors of childhood cancer. N Engl J Med 2006; 355: 1572-82

PanCare

- A multidisciplinary pan-European network of professionals, survivors and their families, founded in 2008
- A legal entity in 2013
- Charitable status in 2014
- Newsletter
- www.pancare.eu

The long-term strategic aim of PanCare is to ensure that every European survivor of childhood and adolescent cancer receives optimal long-term care

Short history

ESLCCC2007 Lund Apr. 2007

I-BFM ELTEC Budapest Oct. 2007

2007 **2008**

PanCare foundation Lund 2008

PanCare meeting # 2-17 in Graz, Modena, Newcastle, Paris, Mainz, Brno, Amsterdam, Bucharest, London, Genova, Amsterdam (again), Wroclaw, Lucerne, Dublin, Vienna and Lisbon

PanCare meeting # 18 Erice, November 2016

PanCareSurFup **2011 - 2017**

ENCCA **2011 - 2015**

PanCareLIFE **2013 - 2018**

Pancare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies

PanCareSurFup

PanCareSurFup

(PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies)

PanCare
Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer

WP1 – Data collection and harmonisation (UMC)
WP2 – Radiation dosimetry (IGR)
WP3 – Cardiac disease (AMC)
WP4 – Second primary neoplasms (UBHAM)
WP5 – Late mortality (ULUND)
WP6 – Guidelines, transition and follow-up (UNEW)
WP7 – Dissemination and training (MBBM)
WP8 – Coordination and management (ULUND)

www.pancaresurfup.eu

PanCareLIFE

- Impairments in female fertility
- Increase knowledge about sperm cryo-preservation
- Hearing loss in young children
- Quality of life
- Risk factors – genetic and non-genetic
- New European guidelines to help preserve fertility

ENCCA

(European Network for Cancer Research in Children and Adolescents)

HEALTH.2010.2.4.1-3 Structuring clinical research in paediatric and adolescent oncology in Europe

- Network of Excellence
- > 30 Partners in 11 countries
- Maximum contribution €12,000,000, 5 years
- CCRI in Vienna is the coordinating partner
- QoL/QoS in medulloblastoma (Colin Kennedy)
- Survivorship Passport (Riccardo Haupt)
- 2011-2015

Co-funded by
the European Union

Consumers, Health and Food
Executive Agency

SIOP Europe

St. Anna Kinderkrebs Forschung

European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment
ExPO-r-Net

Call: 4.2.2.7. Pilot networks of cooperation under Directive 2011/24/EU

European Commission

SIOPE

(European Society for Paediatric Oncology)

SIOPE

- Only pan-European Organisation dedicated to Childhood Cancer
- Over 1,500 SIOPE members (paediatric haemato-oncology professionals) from all over Europe

The SIOPE Strategic Plan – *A European Cancer Plan for Children and Adolescents*

- A long term sustainable strategy with 7 objectives to:
  - Increase cure rate in patients with poor prognosis malignancies
  - Increase quality of life (cure) in survivors
  - Tackle inequalities

Pancare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies

PanCareSurFup

PanCare

Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer

Thank you for your attention!