Long-Term Follow-Up and Quality of Survivorship – A Major Goal

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History of Long-Term Follow-Up

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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Background

• With conventional treatment 2/3 of childhood cancer survivors (CCS) suffer at least one late complication; for 25% it is a serious or life-threatening complication

• With up to 80% survival in developed countries, the number of CCS is growing and it is estimated that 300-500,000 CCS are living in Europe now
Why we do follow-up

- Increased knowledge of long-term consequences of the treatment
- Increased knowledge of the effect of interventions
- Include new knowledge in the next treatment protocol
- Benefit the quality of the survival

- Children are still growing and developing
- They have most of their lifes ahead of them
- Better to be active prospectively than to play catch up
- Long-term follow-up is part of good patient care and quality of survival
What are the potential late effects of treatment?

- Late mortality
- Second cancers
- Heart problems
- Hormonal problems
- Mental and psychological problems
- Lung problems
- Musculo-skeletal problems
- Kidney problems
- Psychosocial problems
- Generally speaking, the most affected are those who
  - have received radiotherapy to the brain and/or central nervous system
  - blood or bone marrow transplantation
  - sarcomas

Some of these problems may not become obvious until after 20-30 years of follow-up!
Who needs Follow-Up?
- 1/3 needs no or very little follow-up for late effects after treatment and may even experience a post-traumatic growth after the experience
- 1/3 needs focused follow-up for potential late effects and
- 1/3 needs extensive follow-up and medical care

Fragmented Follow-Up
- But - This follow-up is fragmented in Europe, both within and between countries
Why we should do long-term follow-up in CCS

• Their median age now is around thirty
• Will they experience diseases that affect us all at:
  – Earlier age?
  – Higher frequency?
  – More severely?
The benefit of follow-up

- **Primary prevention** – Avoid getting sick in the first place, e.g. never start smoking, avoid excess UV-radiation, immunization, genetic predisposition to late complications/e.g. optimally we should know who should not receive anthracyclins in the first place

- **Secondary prevention** – Having been exposed; what can I do to avoid a certain outcome? Detect and address an existing disease before it produces symptoms, screen for cancer/e.g. breast cancer screening after radiotherapy to the chest

- **Tertiary prevention** – Reduce damage and prevent deterioration caused by symptomatic disease, e.g. rehabilitation after stroke to limit disability and maximise remaining capabilities
What is the status for long-term follow-up in Europe?

- Long-term follow-up is very fragmented and even non-existent in places
- Big differences even within countries
- Guidelines are lacking or differ between recommendations although efforts are made to harmonise them
- Transition services are not available in many places
- Models of care suited to different circumstances remain to be decided
- Differentiated follow-up depending on the treatment is/will be necessary
- The survivors are out there but maybe not in the right place
Different models for long-term follow-up in Europe

- Nurse lead
- Paediatric oncologist lead
- Other types of physicians, e.g. endocrinologist
- GPs
- In the paediatric setting vs in the adult setting
- Outpatient clinic
- Telephone interviews
- Life-long or limited in time?
- That follow-up is done is more important than how it is done!
Rationale for LTFU of New Drugs

- Prospective follow-up is possible instead of playing catch up
- Mode of action might predict what to look for
- The first novel drugs used have shown that late complications do exist
Challenges

• The impact and burden of previous or concurrent therapy must be factored in
• Difficult to understand the weight of each separate part of the treatment
• The timeline for LTFU for new drugs may be different from that of conventional therapy
• Understanding which outcomes to monitor specifically for a new drug
What is desirable for the future

• A Survivorship Passport for all CCS including a summary of the treatment received, which follow-up that this treatment mandates and catchment of different outcomes over time

• A sustainable system whereby long-term follow-up of CCS involved in different trials is made possible

• A system for the support of CCS enabling them to reach their full potential
What is available to move forward

• The Survivorship Passport coming from the ENCCA project; needs adding an outcomes module

• A growing number of individuals, organisations and projects dedicated to LTFU, Guidelines and Quality of Survivorship; e.g. CDDF WG3, PanCare, SIOPE, CCI
Thank you for your attention!