Executive Summary

I. Living With Survival: The Childhood Cancer Survivor
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A. Introduction & Background
- The good news is that children under the age of 15 who are diagnosed with cancer have an 80% chance of long-term survivorship.
- There are currently 270,000 people in the US who have survived childhood cancer.
- The development chemotherapy has been a key factor in the increase in pediatric survivorship.
- Once population of pediatric survivors started growing, they became the basis for studies in long-term effects of cancer treatments.
- All treatments—chemotherapy, radiation, surgery and bone marrow transplantation—have potential late effects.
- At least 2/3 of childhood cancer survivors will have at least one late effect.
- 1/3 of them will have 2 or more late effects.
- 1/3 will have a very serious late effect.
- Incidence of late effects increases with age, as patient gets further and further out from diagnosis and treatment. Effects often are silent for years and years, only to become apparent decades after therapy has ended.

B. Children’s Cancer Survivor Study (CCSS)
- Source of a great part of the information available to pediatric oncologists concerning childhood cancer survivorship.
- Comprehensive study started in 1994—multiinstitutional, involves about 25 institutions across the country
- 13,000-15,000 patients have been enrolled, must be at least 5 years out from diagnosis.
- Major finding: 43% of 9,5000 young adult survivors were found to have a moderately severe late effect (some physical, some mental/emotional).
C. 2001 *Journal of Clinical Oncology* Report

- Used two studies to look at 34,000 long-term survivors (patients diagnosed at least 5 years earlier with a pediatric malignancy).
- Both studies showed an almost eleven-fold increased risk of "excess mortality" (an event which causes their death).
- In 2/3 of the patients, the excess mortality was due to a recurrence of their initial cancer.
- 1/5 of the patients died from either the development of a second malignancy or some other treatment-related cause.
- In 60% of the patients who died from treatment-related causes, their death was due to the development of a secondary malignancy—a second diagnosis of a different form of cancer, not a recurrence.
- For patients who developed a second malignancy, they found that those who developed a solid tumor seemed to be related to patients who had undergone radiation therapy because a lot of the tumors developed on the radiation therapy field.
- In some of the patients, the second malignancy took the form of a form of leukemia and that seemed to be more chemotherapy-related, and specifically related to two classes of drugs—alkylator or epipodophyllotoxins.
- Those who suffered pulmonary mortalities were associated with radiation to the thorax or chest and/or were treated with a chemotherapeutic agent called bleomycin.
- Cardiac mortalities were associated with chemotherapeutic agents in the anthracycline family and/or had radiation to the chest.

D. Potentially Life-threatening Late Effects

- **Second Malignancies**
  - **Leukemia**—related to chemotherapy
    - Usually in the form of myeloid leukemia or AML.
    - Families of drugs found to be related: alkylating agents, heavy metals, epipodophyllotoxins, anthracyclines.
    - Short latency period (period of time from when treatment is given and effect occurs.
    - Latency was just months to few years, and then risk seems to dissipate.
    - Signs of leukemia: pallor/fatigue, recurrent fevers/infections, easy bruising, excessive bleeding, bone pain.
  - **Radiation Induced Second Malignancies**
    - Forms include skin cancer, soft tissue sarcomas, bone tumors, brain tumors, thyroid cancer, breast cancer.
    - Long latency period—often 20 years or more.
c) Lung Toxicity

- Caused by exposure to a number of chemotherapeutic agents (bleomycin, BCNU, CCNU, Busulfan).
- Also caused by radiation to the chest.
- Symptoms include exercise intolerance, shortness of breath, frequent coughing or wheezing and frequent lung infections.

d) Heart Toxicity

- Mainly caused by exposure to group of drugs called anthracyclines (Doxorubicin, Adriamycin, Daunorubicin) and/or chest irradiation.
- Symptoms include shortness of breath, dizziness, fainting, fatigue, chest pain, swollen ankles, persistent cough, racing heart or irregular heartbeat.

E. Looking Forward—Pediatric Survivors

- Many of the issues pediatric survivors are at risk for have potentially modifiable outcomes.
- Can be screened for second cancers and hopefully be treated and cured.
- Can be counseled on healthy lifestyle choices (sunscreen, physical activity, diet).
- Long-term patient follow-up is an issue—survivors will want to maintain contact with oncologists as new information on late effects continues to emerge.
- Every survivor has different needs based on his or her individual risk assessment.
- Every survivor needs a LIFEPLAN—systematic plan for screening, surveillance, counseling and prevention based on survivor’s individual cancer history, family history and lifestyle.

F. VCU Health System Pediatric Survivorship Clinic

- Jointly run by Dr. Nancy Dunn and Anne Mauck, PNP.
- See patients who are a minimum of five years out from diagnosis and at least 2 years out from therapy.
- No upward age limit.
- Meets almost every Wednesday at the Nelson Clinic
- Call 828-9300 for appointment.
- Patients receive Treatment Passport—patient treatment summary and risk information tailored for each patient.