

We can cure the cancer...
now what?

Survivors of Childhood and AYA Cancer:
Risk, Surveillance and Education

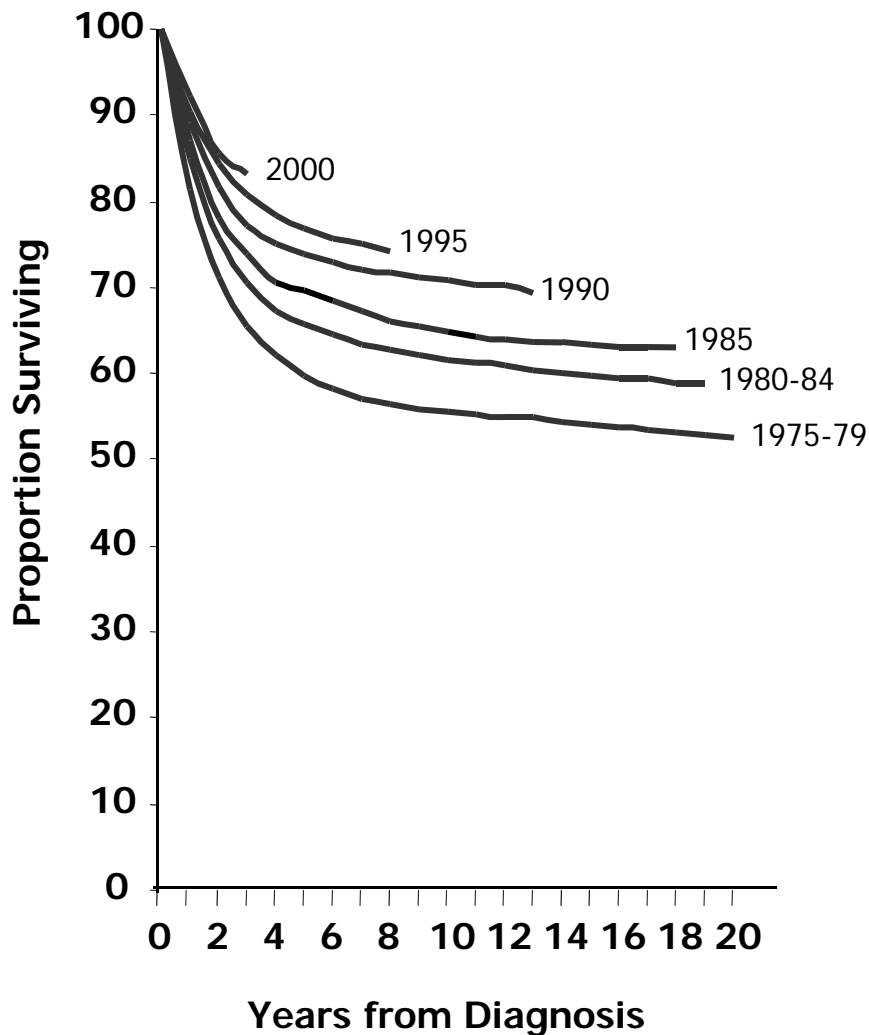
Tara Henderson, MD. MPH.

May 12, 2012



THE UNIVERSITY OF
CHICAGO
COMER
CHILDREN'S
HOSPITAL

Childhood Cancer Survivors



Survivorship Statistics*

- 12,000 new pediatric cases/yr
- Cure rate approaching 80%
- Over 350,000 childhood cancer survivors in the U.S.
- 1 in 900 is a survivor of childhood cancer
- 1 in 570 is a childhood cancer survivor (ages 20 to 34 years)

* Source: NCI Office of Cancer Survivorship

“Cost of Cure” = Late Effects

Late effect:

- Health problem following the cancer and cancer therapy
- Often not clinically apparent until **20-30 YEARS** after the cancer

What is the cost of cure?

Based on survivors treated between 1970-86 in the North American Childhood Cancer Survivor Study:

- By 30 years after their cancer:
 - 3/4 have at least one chronic health condition
 - 2/5 have a severe or life threatening condition
- 8 times more likely to have a severe or life threatening health condition than their siblings

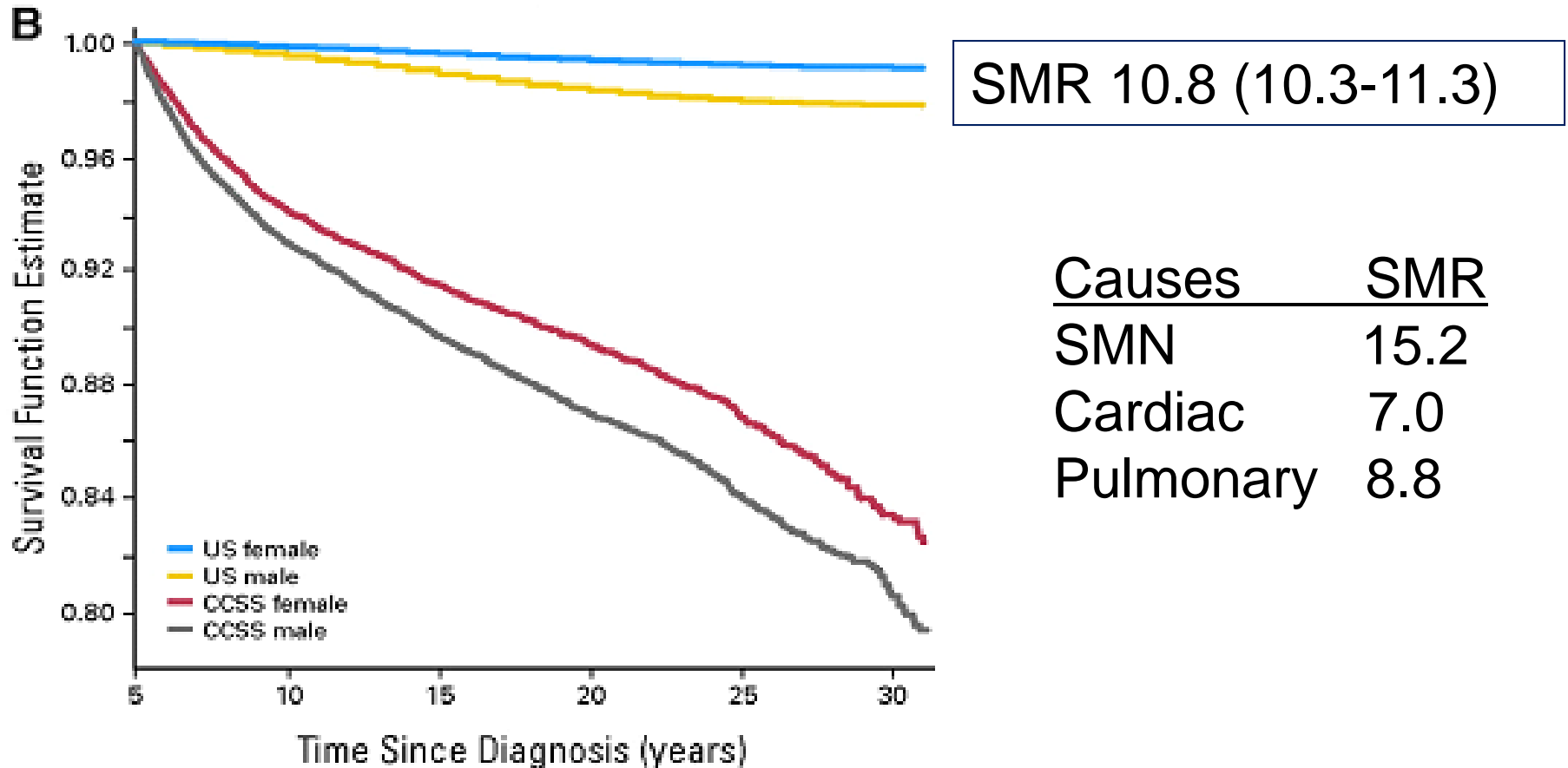
Oeffinger, NEJM, 2006

Armstrong, JCO, 2009

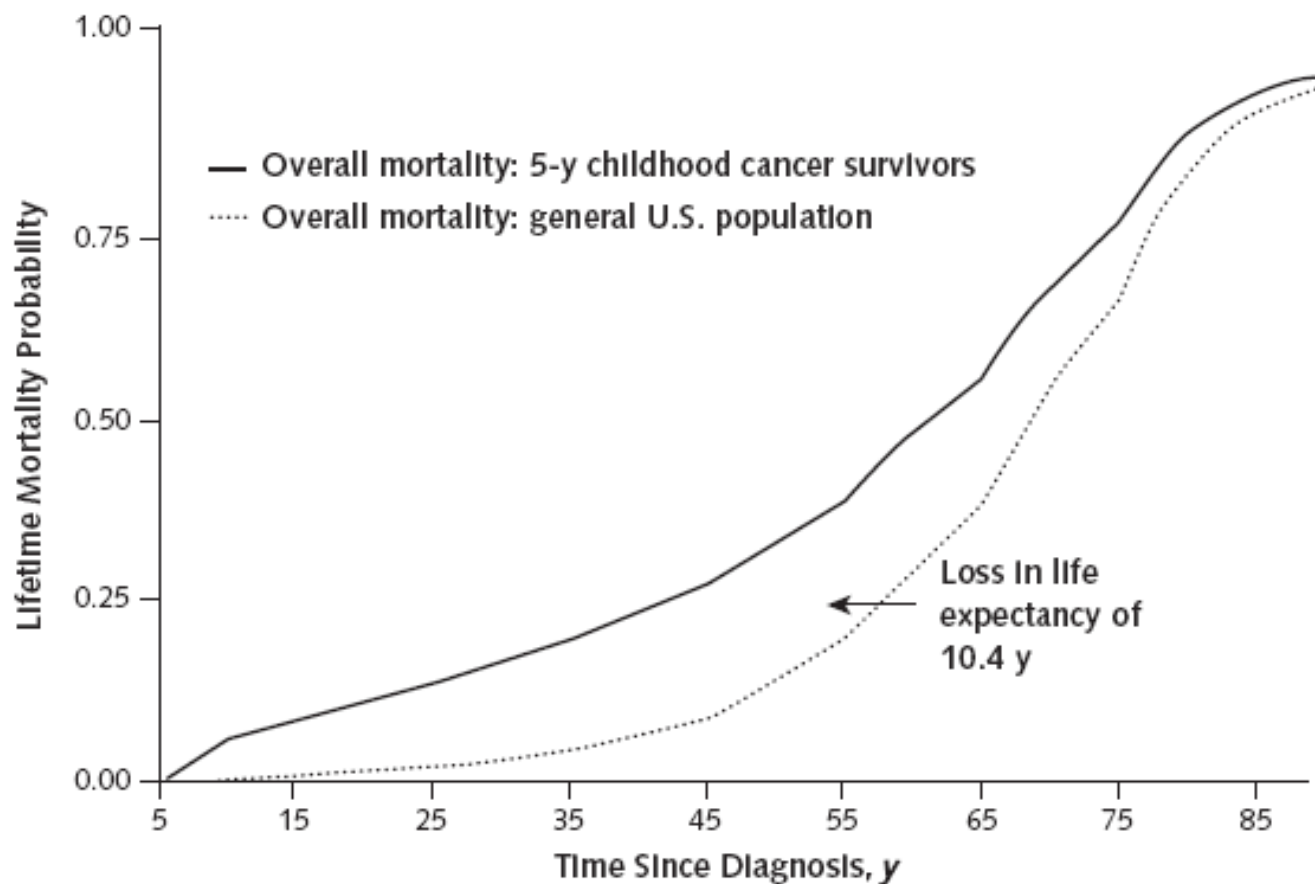
Wide Array of “Late Effects” in Childhood Cancer Survivors

- Heart problems
- Pulmonary/breathing problems
- Increased infection risks
- Fertility/reproduction problems
- Second cancers
- Endocrine/hormone problems
- Kidney problems and hypertension
- Obesity
- Bone and skeletal problems
- Psychological and learning issues
- Dental problems
- Hearing Problems
- Vision/Eye Problems

Late Mortality of 5+ Year Childhood Cancer Survivors vs. US Population



Overall Lifetime Mortality Probability for 5+ Year Childhood Cancer Survivors and the General US Population



Survivors of Pediatric Cancer

- High-risk, growing population
 - Wide array of potential late effects
 - Elevated early mortality
 - Lack of studies on early aging
 - Clinically silent period for many late effects
- ❖ Improve morbidity and mortality of population with secondary or tertiary prevention and early diagnosis/intervention

Goals of 'Risk-Based' Care

- Monitor for recurrence of cancer
- Surveillance for second cancers and late effects
 - Early diagnosis and intervention
- Prevention
 - Lifestyle, health behaviors
- Education

Institute of Medicine, 2003

Curr Probl Cancer 27:143-167, 2003

CA Cancer J Clin 54:208-236, 2004

Standardized Screening

www.survivorshipguidelines.org

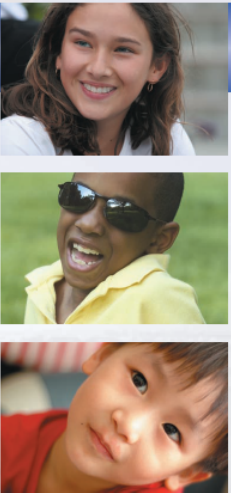
Long-Term Follow-Up Guidelines
for Survivors of Childhood, Adolescent,
and Young Adult Cancers

Version 3.0 – October 2008

CureSearch
Children's Oncology Group

www.survivorshipguidelines.org

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THERAPY BASED LONG TERM FOLLOW UP
(2nd Edition, April 2005)

Practice Statement

UNITED KINGDOM CHILDREN'S CANCER STUDY GROUP
LATE EFFECTS GROUP


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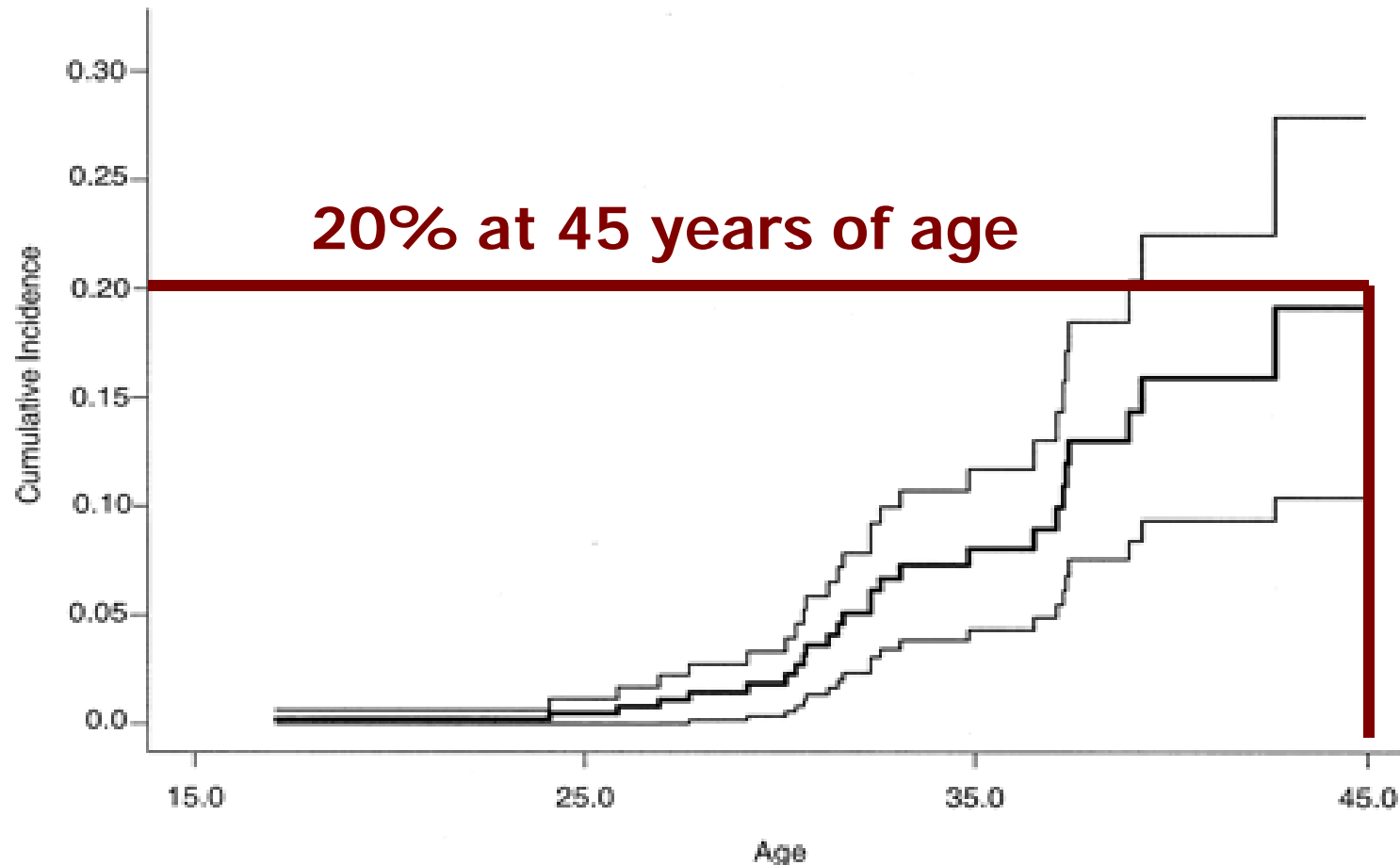
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Supported by an educational grant from Pfizer.



Long term follow up care of survivors of childhood cancer
Guideline No. 76
Publication: January 2004
1 899893 83 0

Breast Cancer After Childhood Cancer: A model for cancer survivorship care



Survivorship Care Plans



Passport for Care Admin Login (1/1/2008)
Last login on: 06/26/2008 11:01 AM
Download for Testing Site
Care Summaries | Security List | Clinic List | Consent Management | User Administration | System Notifications | Help Desk/FAQ

Care Summaries | Guidelines Administration | Guidelines Screening Administration

Peter Smith | (000000-0000-0000) | AMMIGATED | CONFIRMED

Summary of Treatment | Additional Information | Consolidation Summary | Follow-Up Guidelines | Access History

Abbreviated Summary of Treatment

SECTION ONE

DEMOGRAPHIC INFORMATION
First Name: Peter | Last Name: Smith | Sex: M | Date of Birth: 06-25-1984 (year-old years)
Medical Record Number: 123456789

CANCER DIAGNOSES
Diagnosis: Leukemia | Date of Diagnosis: 07-10-2003 (year-old years) | Date Therapy Started: 01-24-2004 (year-old years)
Acute lymphoblastic leukemia

SECTION TWO

SECTION THREE
Please enter all treatment agents for every cancer experience.

SURGERIES
PROCEDURE: Central venous catheter | LATERNALITY (if applicable): R

CHEMOTHERAPY
Drug Name: Doxorubicin, Irinotecan
1 Doxorubicin: 924 mg/m2
2 Irinotecan: 60000 units/m2
3 Hydrocortisone (low dose IV): 5000 mg/m2

RADIATION
Type: Tx, external x-ray or radio to Gy, divide dose by 100 (example: 3400 cGy = 3400 mGy = 34 Gy)
SITE/AREA: Neck, Neck/w/ Neck
1 Neck: Neck (Sunder): 45.00 Gy
2 Head/Neck: Cranial (whole brain): 24.00 Gy

HEMATOPOIETIC CELL TRANSPLANT

OTHER THERAPEUTIC MODALITY

COMPLETE EVALUATIONS

NAME: Peter Smith
DIAGNOSIS DATE: 07-10-2003
SEX: Male
AGE DIAGNOSED: 18-19 (Years)
DOB: 06-25-1984
DIAGNOSIS: Leukemia Acute lymphoblastic leukemia

HISTORY

GENERAL
Assessment of nutritional status: Every six months until growth is completed, then yearly
Skin/Neck: Skin lesions, Changing moles (asymmetry, bleeding, increasing size, indistinct borders)
Tenderness or swelling at previous catheter site: Tenderness, Vascular malformation, Infection of related cath or the test
Eyes/Ears/Nose/Mouth/Throathead: Rhinorrhea, postnasal discharge, Visual changes (increased acuity, halos, diplopia), Xerophthalmia
Cardiovascular: Weakness of hands, feet, nose, lips, cheeks, or earlobes related to stress or cold temperatures
Musculoskeletal: Bone pain (especially in irradiated field)

POTENTIAL LATE EFFECT
Growth hormone deficiency
Osteoporosis
Cataracts
Hypothyroidism
Hypertension
Hypogonadism
Hypoparathyroidism
Hypoadrenalism
Hypopituitarism
Hypothalamic-pituitary axis dysfunction

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HEMATOPOIETIC CELL TRANSPLANT

OTHER THERAPEUTIC MODALITY

AT&T 12:11 PM

iCANCER My Profile

New Profile Settings

iCANCER

About Me Diagnosis Treatments Contacts

Lab Results Issues Resources Appointments

iPod 9:00 PM

My Profile Medical Issues Edit

Joint pain 6/26/06

Fever 4/25/05

Description Headache

Severity Mild

Onset Date March 26, 2004

Resolution Date March 27, 2004

Outcome Recovered

Nausea 2/20/04

Are survivors receiving risk based care?

- 85% of survivors receive care in the community Nathan et al. JCO 2009
- 15% report having a treatment summary or survivorship care plan Nathan et al. JCO 2009
- In a survey of over 3000 family physicians and internists, vignette of a women survivor of Hodgkin lymphoma who received chest radiation and anthracycline chemotherapy:
 - Less than 20% aware of breast cancer screening recommendations
 - Less then 15% aware of cardiac screening recommendationsHenderson et al ASCO 2011

University of Chicago Childhood Cancer Survivor Center

- Cancer-center based long-term follow-up program
 - Patients seen in partnership with primary care
- Opened in 2006
 - Section of Pediatric Heme Onc Initiative
 - Philanthropic Support
 - Research
 - NCI support
 - University of Chicago Cancer Center Support
- See survivors of childhood and AYA cancer (dx < 30 years)
 - At least 2 years off therapy and no evidence of disease
 - No age limit
 - Patient from outside UC, medical records requested



University of Chicago Childhood Cancer Survivor Center

- Focus on:
 - Education of family and patient
 - Screen for cancer re-occurrence
 - Screen for late effects, second cancers, cognitive & psych issues
 - Education of PMD
 - Psychologist and/or social worker for each patient
 - Close collaboration with UC sub-specialists in pediatrics and medicine
 - Cardiology, endocrine, pulmonary, dermatology, ophthalmology, ENT

University of Chicago Childhood Cancer Survivor Center

SURVIVORSHIP CARE PLAN

Date of preparation:

Name: JANE DOE	Date of Birth: 1/1/1986
Cancer Diagnosis: Hodgkin lymphoma, Nodular Sclerosis. Stage IIIA with bulk	
Treatment centers: University of Chicago	
Date of diagnosis: 6/20/2001	Age at diagnosis: 16 years
Relapse: N/A	
Date of completion of therapy: 10/15/2001	

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Screening Recommendations**

- Annual labs to include: CBC, comp profile, TSH, urinalysis, lipid profile, insulin, CRP, 25-OH vitamin D level, testosterone
- Echocardiogram/EKG every 2 years
- Mammogram + breast MRI every year
- Pulmonary Function Test every 1-2 years
- Bone density study (DXA) every 2 years
- Dental exam yearly; cleaning every 6 months
- Eye exam every year
- Counseling and treatment as indicated
- Dermatology exam every year
- Pap smear yearly
- Influenza vaccine yearly



THE UNIVERSITY OF
CHICAGO
CHILDREN'S
HOSPITAL

University of Chicago Childhood Cancer Survivor Center

- To date:
 - Follow over 250 cancer survivors
 - Patients treated across US
 - All ages
 - Growing prospective database and biobank
 - Childhood Cancer Survivor Study site
 - Now seeing survivors of young adult cancer

Thank you!
