Long-term survival has improved over time

15-Yr cumulative mortality:
- 1970s, 10.7% (10.1–11.4)
- 1980s, 7.9% (7.4–8.3)
- 1990s, 5.8% (5.4–6.3)

P < 0.001
Hope that Future Generations of Children will do even better
US cancer survivors, 17 million
(>75% diagnosis: age 55 years)

Survivors of childhood cancer, ~500,000
(BUT anticipated future years of life: >55 years)

Source: Cancer.gov
Effects of treatment on growing bodies

- **Brain:** intrathecal chemotherapy, surgery, tumor
- **Hearing:** platinum-agents like cisplatin
- **Heart:** anthracyclines like doxorubicin
- **Lungs:** bleomycin, busulfan
- **Fertility:** alkylating agents like cyclophosphamide
- **Bones:** steroids, high-dose methotrexate

**Radiation – effects on all of these!**
Effects of treatment on growing bodies

• Radiation & second cancers:
  • Brain: annual history and exam
  • Thyroid: annual exam to feel for nodules
  • Breast: after puberty, annual exam for lumps; consider breast imaging (mammography, MRI) starting age 25
  • Colorectal: consider screening starting age 30
  • Skin: annual exam for moles

Consider visit with genetic counselor even if no family history

No one gets all these problems
No one is completely unaffected
Most survivors lead healthy lives
Many families identify end of treatment as a time of new uncertainty, frustration and stress

“We lived with these people (staff) for 8 months, and then they say ‘OK, you’re done, see you. We will see you in 3 months. Bye.’ …..hey, wait a minute. This is really not over for us.”
Moving from Cancer Patient to Survivor

**Transitions**

- End of treatment
- Oncology team
- Pediatric care

Return to “normal”
Primary care & survivor program
Adult care

**Things to learn about**

- Cancer treatment summary & late effects
- Follow-up schedule
Survivor Knowledge of Past Cancer History often Limited

Diagnosis
- 91% knew (72% detailed knowledge)
- 2% cancer
- 7% unaware

Treatment exposures
- Radiation ~90% aware (only 70% knew site)
- Anthracycline chemotherapy <50% aware
- Splenectomy (surgery) ~2/3 aware

Kadan-Lottick, Journal of the American Medical Association 2002
Survivorship Care Plan

- Tool to improve knowledge, awareness
- For patients & other providers
• **Recommended follow-up and identify who is responsible**

<table>
<thead>
<tr>
<th>Service</th>
<th>Frequency</th>
<th>Provider to Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Oncology Follow-up</strong></td>
<td>9/6/2017</td>
<td>Seattle Children’s</td>
</tr>
<tr>
<td></td>
<td>AFP and exam yearly</td>
<td>Summer/Fall 2018</td>
</tr>
<tr>
<td></td>
<td>through 5-years off-therapy</td>
<td></td>
</tr>
<tr>
<td><strong>Survivorship</strong></td>
<td>9/6/2017</td>
<td>Seattle Children’s</td>
</tr>
<tr>
<td></td>
<td>Yearly with labs as</td>
<td>Summer/Fall 2018</td>
</tr>
<tr>
<td></td>
<td>indicated</td>
<td></td>
</tr>
<tr>
<td><strong>Pulmonary Function (PFT)</strong></td>
<td>Never</td>
<td>Seattle Children’s</td>
</tr>
<tr>
<td></td>
<td>Baseline requested for</td>
<td>Summer/Fall 2018</td>
</tr>
<tr>
<td></td>
<td>2018</td>
<td></td>
</tr>
<tr>
<td><strong>Immunizations:</strong></td>
<td>All routine vaccines are</td>
<td>Primary care provider</td>
</tr>
<tr>
<td></td>
<td>ok</td>
<td>Anytime</td>
</tr>
<tr>
<td><strong>Audiology/Hearing</strong></td>
<td>2013</td>
<td>Seattle Children’s</td>
</tr>
<tr>
<td></td>
<td>Repeat at 5-years off-therapy</td>
<td>Summer/Fall 2016</td>
</tr>
</tbody>
</table>

**Wellness Screening**

Based on National Cancer Institute, U.S. Preventive Task Force, and National Institutes of Health recommendations.

<table>
<thead>
<tr>
<th>Test or Exam</th>
<th>Frequency</th>
<th>Provider to Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Well Physical</strong></td>
<td>Yearly</td>
<td>Primary Care</td>
</tr>
<tr>
<td>Skin, eyes, mouth, thyroid, carotids, heart, lungs, breast, abdomen, lymphatics, blood pressure, immunization status</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Dental and Oral</strong></td>
<td>Twice a year or as</td>
<td>Dentist</td>
</tr>
<tr>
<td>indicated</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Contact/Resources**

Seattle Children’s Hospital Cancer Survivor Program
4800 Sand Point Way NE, MB 8.501, Seattle WA 98105
Phone: 206-987-2106 Fax: 206-987-3946
www.seattlechildrens.org/cancersurvivorprogram

For more detailed information on many of these topics, please see Health Links at www.survivorshipguidelines.org

Prepared: 9/25/2017
Prepared By: Eric Chow

**CC Providers** No data reported
Development of Evidence-based Guidelines

- Children’s Oncology Group (COG)
  - Clinical trials network uniting >200 pediatric centers across North America, Australia, New Zealand, Europe, Middle East.
  - Supported by federal dollars (National Institutes of Health) and private philanthropy
  - Test new therapies in large clinical trials
  - Develop evidence-based supportive care guidelines
Updated every 5 years by pediatric survivorship experts in COG

Basis of most North American survivorship care
### Individual sections for each type of treatment, including radiation & surgeries

#### Radiation

<table>
<thead>
<tr>
<th>Section</th>
<th>Therapeutic Exposure</th>
<th>Potential Late Effects</th>
<th>Periodic Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Chest</td>
<td>Cardiotoxicity</td>
<td>HISTORY</td>
</tr>
<tr>
<td></td>
<td>Abdomen</td>
<td>Cardiomyopathy</td>
<td>If dose ≥15 Gy:</td>
</tr>
<tr>
<td></td>
<td>Spine (thoracic, whole)</td>
<td>Subclinical left ventricular dysfunction</td>
<td>Shortness of breath</td>
</tr>
<tr>
<td></td>
<td>TBI</td>
<td>Congestive heart failure</td>
<td>Hypoxia on exertion</td>
</tr>
<tr>
<td></td>
<td>(TBI is included for cumulative dose calculation purposes only; this section is not applicable to patients who received TBI alone)</td>
<td>Pericarditis</td>
<td>Orthopedic pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pericardial effusion</td>
<td>Chest pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Vascular disease</td>
<td>Palpitations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Atherosclerotic heart disease</td>
<td>If under 28 yrs: abdominal symptoms (nausea, vomiting)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Myocardial infarction</td>
<td>Yearly</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Arrhythmia</td>
<td></td>
</tr>
</tbody>
</table>

#### Physical

<table>
<thead>
<tr>
<th>Section</th>
<th>Therapeutic Exposure</th>
<th>Potential Late Effects</th>
<th>Periodic Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td></td>
<td></td>
<td>HISTORY</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>If dose ≥15 Gy:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Blood pressure</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Cardiac exam</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yearly</td>
</tr>
</tbody>
</table>

#### Screening

<table>
<thead>
<tr>
<th>Section</th>
<th>Therapeutic Exposure</th>
<th>Potential Late Effects</th>
<th>Periodic Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td></td>
<td></td>
<td>HISTORY</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>If dose ≥15 Gy:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Blood pressure</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Cardiac exam</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yearly</td>
</tr>
</tbody>
</table>

#### Cardiac Risk Factors

- **Health Links:**
  - Heart Health
  - Cardiotoxic Risk Factors
  - Diet and Physical Activity
  - Dental Health

#### Counseling

- **Maintain appropriate weight, blood pressure and heart-healthy diet.**
- **Regarding exercise:**
  - Regular exercise is generally safe and should be encouraged for patients who have normal LV systolic function.
  - Survivors with asymptomatic cardiomyopathy should consult cardiologist to define limits and precautions for physical activity.
  - Cardiology consultation may be reasonable to define limits and precautions for physical activity for high-risk survivors (i.e., those requiring an ECHO every 2 years) who plan to participate in intensive exercise.
  - If QT interval is prolonged: Caution regarding use of medications that may further prolong the QTc interval (e.g., tricyclic antidepressants, antifungals, macrolide antibiotics, metronidazole).

#### Potential Considerations for Further Testing and Intervention

- Optimize cardiovascular risk factors including blood pressure, lipid profile, and blood glucose.
- Cardiac MRI as an adjunct imaging modality when echocardiographic images are suboptimal.
- Cardiology consultation in patients with subclinical abnormalities on screening evaluations, left ventricular dysfunction, dysynchrony, or prolonged QTc interval.
- Cardiology consultation is required for coronary artery disease in survivors who received ≥35 Gy chest radiation alone or ≥15 Gy chest radiation plus anthracyclines.
- In survivors with cardiac disorders, consult cardiologist to advise regarding need for endocardial prophylaxis.
- Evaluate patients only for those who are pregnant or planning to become pregnant, additional cardiology evaluation is indicated in patients who received:
  - ≥250 mg/m² anthracyclines
  - ≥35 Gy chest radiation, or
  - Anthracycline (any dose) combined with chest radiation ≥15 Gy
- Evaluation should include a baseline echocardiogram (pre- or early pregnancy). For those without prior abnormalities and with normal pre- or early pregnancy baseline echocardiograms, follow-up echocardiograms may be obtained at the provider’s discretion. Those with a history of systolic dysfunction or with pre- or early pregnancy systolic dysfunction are at higher risk for pregnancy-associated cardiomyopathy. Such individuals should be monitored periodically during pregnancy and delivered by trained providers to improve pregnancy outcomes.

#### System Score

**SCORE = 1**
Value of Comprehensive Survivorship Care

- Review past cancer history (and screen for recurrence)
- Review potential treatment-related complications, many of which may be preventable or treatable
- *Increase* patient / family awareness & knowledge
- *Increase* adherence to recommended screening

Landier, Journal of Clinical Oncology 2015
Seattle Children’s Survivor Program

Founded 20 yrs ago by Dr. Deb Friedman with support from the LIVESTRONG foundation

Anyone treated for childhood cancer or blood disorder requiring chemotherapy, radiation is welcome to be seen (doesn’t matter if you were originally treated at SCH or elsewhere)

Clinic in Seattle 4 days/wk, plus quarterly outreach clinics to TriCities and Federal Way, plus periodic visits to Montana

In 2018, we had ~450 visits and are on-target to well exceed that this year

We had our 1st Moving Beyond Cancer to Wellness event in 2008 (and this is our 5th event!!)
Transition to Adult Care? Barriers…

• While some pediatric survivorship programs offer life-long care, this is not an option for many…
  • Adult primary care providers often become responsible for future coordination
  • Sometimes a hybrid model (combined pediatric center + affiliated adult program)
  • Rarely medical oncologists

• Other issues…
  • Perceived lack of knowledge on part of survivor & future provider
  • Difficult “letting go” on part of pediatric team as well as patient / family

Source: CDC.gov
Tips for Improving Transition

• Begin conversation early… recommended to start at age 14
  • Discuss with your pediatric oncology team
  • Discuss with your primary care provider
  • Know what resources exist in college if applicable
  • Determine if you need adult subspecialty care and where to get it
  • Understand insurance and whether you can stay on parental insurance until age 26
  • Explore guardianship issues if applicable before age 18

• Be your own advocate
  • Have a copy of your survivorship care plan (or know where you can get one)
  • Patient-centered electronic health records
Importance of healthier lifestyles

Things to avoid:
- Tobacco / smoking (e-cigs too)
- Sun tanning
- Excess alcohol

Things to get:
- Exercise
- Fruits / vegetables
- Follow-up care

"And then when we turn 30 and get lung cancer, we can sue the tobacco companies."
For Survivors of Childhood Cancer, Walk

Regular exercise, such as brisk walking for an hour, improved long-term survival in those who had childhood cancers.

Scott, JAMA Oncology 2018
Cancer treatment

Late effects screening

Develop-ment of late effects

Treat-ment of late effect

Adopt healthier lifestyle

Improve coordination with primary care & other specialists to care for survivors

Improve screening

Improve treatments with less future side effects
Summary: 7 Tips for Success

1. Visit survivorship clinic… and repeat
2. Share your survivorship care plan with your other providers (especially primary care… important to re-establish care)
3. If you are ≥14 years old, start talking to your pediatric providers about eventual transition (if applicable) to adult providers
4. Get more exercise (more on that from Dr. Ketterl!!)
5. Try to eat healthier
6. Don’t smoke (including e-cigarettes)
7. Don’t depend on your parents to organize your healthcare forever…
It’s not the years in your life that count.
It’s the life in your years.

– A. Lincoln
Every child begins the world again
– Henry David Thoreau
Online Resources

- Current pediatric cancer treatment

- Survivorship
  - Children’s Oncology Group: www.survivorshipguidelines.org/
  - NCI/NIH: www.cancer.gov/types/childhood-cancers/late-effects-pdq
  - Childhood Cancer Survivor Study: https://ltfu.stjude.org/
  - Scholarships: www.ped-onc.org/scholarships
  - Young Adults:
    - Cancer Care http://www.cancercare.org/tagged/young_adults
    - First Descents https://firstdescents.org/
    - Stupid Cancer http://www.stupidcancer.org/

- Other topics
  - Guardianship: https://thearc.org/
  - Health insurance: Kaiser Family Foundation http://kff.org/
THANK YOU