Cancer Survivors
How to Avoid Lost in Transition

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Medical Director, University Health, UGA
Clinical Assist Professor, Ga Regents Univ
Captain, MC, United States Navy (RET)

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Kathelen V Amos Children’s Chair for Survivorship
Medical Director of Cancer Survivor Program
Professor of Pediatrics
Outline

• Case

• Health of Adult Survivors of Pediatric Cancer

• What is Survivor care

• What is SurvivorLink™

• College Health and Student Survivors
Photo deleted (Survivor Tattoo)
Pediatric and Adolescent Cancer

Trends in 5-year relative cancer survival rates

- Overall, 80% of patients diagnosed with pediatric or adolescent cancer will be long-term survivors
- 1:530 young adults is a survivor of pediatric or adolescent cancer
Childhood Cancer Survivor Study (CCSS)

- 26 participating Centers
  - 14,370 survivors of pediatric and adolescent cancer
  - Diagnosed between 1970-1986
  - 3,737 sibling controls
- Medical Record Abstraction
  - Cancer Dx and Rx
- Self Report
  - Health status
  - Quality of life

NCI grant (U24 CA55727)
Dr. Forehand’s Concerns

• Is her cancer back?

• Does she have a second malignant neoplasm?

• Does she suffering from a late effect of her cancer treatment?
Adult Survivors of Childhood Cancers

• Increased risk of mortality
  – Armstrong et al. JCO 2009

• Increased risk of Second Malignant Neoplasm
  – Neglia et al. JNCI 2001
  – Friedman et al. JNCI 2010

• Increased risk of a chronic health condition
  – Oeffinger et al. NEJM 2006
Causes of Mortality in Survivors

Cumulative mortality at 30 years
18.1%

Decreasing rate of death attributable to recurrence or progression of primary disease

Increasing rates of death
- subsequent neoplasms  15.2 X
- cardiac death  7.0 X
- pulmonary death  8.8 X

Armstrong et al JCO 2009
Second Malignant Neoplasm

- Leukemia
- Skin Cancer
- Thyroid Cancer
- Breast Cancer
- Meningioma

Olsen JNCI 2009
We are not finished at “cure”

• What is the cost of cure?
Chronic Health Condition Assessment

• Calculated the frequency of chronic conditions

• Common Terminology Criteria - Adverse Events v 3.0
  – 1 is mild
  – 2 is moderate
  – 3 is severe
  – 4 is life threatening or disabling
  – 5 is death

• 62.3% had a chronic health conditions

• 27.5 % of survivors had a grade 3-5 condition

Oeffinger KC et.al. 2006 NEJM 355 (15) 1572-1582.
# Grade 3 and 4 Conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>RR</th>
<th>95% CI</th>
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<tbody>
<tr>
<td>Major Joint Replacement</td>
<td>54.0</td>
<td>7.6 – 386.0</td>
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<tr>
<td>Congestive Heart Failure</td>
<td>15.1</td>
<td>4.8 – 47.9</td>
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<tr>
<td>Second Malignant Neoplasm</td>
<td>14.8</td>
<td>7.2 - 30.4</td>
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<tr>
<td>Cognitive Dysfunction–Severe</td>
<td>10.5</td>
<td>2.6 – 43.0</td>
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<tr>
<td>Coronary Artery Disease</td>
<td>10.4</td>
<td>4.1 - 25.9</td>
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<tr>
<td>Cerebrovascular Accident</td>
<td>9.3</td>
<td>4.1 – 21.2</td>
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<tr>
<td>Renal Failure or Dialysis</td>
<td>8.9</td>
<td>2.2 – 36.6</td>
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<tr>
<td>Hearing Loss not Corrected by Aid</td>
<td>6.3</td>
<td>3.3 – 11.8</td>
</tr>
<tr>
<td>Legally Blind or Loss of an Eye</td>
<td>5.8</td>
<td>3.5 – 9.5</td>
</tr>
<tr>
<td>Ovarian Failure</td>
<td>3.5</td>
<td>2.7 – 5.2</td>
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</tbody>
</table>

Oeffinger KC et.al. 2006 NEJM 355 (15) 1572-1582.
CCSS – 30 year old survivors

• 2/3 are living with a chronic Health Condition

• ¼ are living with a condition that is
  – Severe
  – Disabling
  – Life threatening
  – Or has resulted in death
Outline

• Case

• Health of Adult Survivors of Pediatric Cancer

• What is Survivor care

• What is SurvivorLink™

• College Health and Student Survivors
Aflac Cancer Survivor Program

- 2 yrs off therapy
- Multidisciplinary
  - Oncology
  - Endocrinology
  - Psychology
  - Social Work
- Research Team
Survivor’s Knowledge

• 72% knew their diagnosis (e.g. Leukemia)
  – 19% knew diagnosis but not type even with prompts

• 94% knew they had chemotherapy
  – If presented with a drug name accuracy was 8-33%

• 89% knew they had radiation
  – Of those 70% could recall the site

Kadan- Lottick JAMA 2002
Survivor Healthcare Plan (SHP)

1. Cancer Diagnosis and Treatment Summary

2. Individualized Late Effects Risk Profile

3. Individualized Surveillance Plan
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
Every Survivor Needs a:

• **SHP**
  
  – Directs long-term follow-up in an evidenced based way
  
  – Essential in periods of transition
Beth needs to share with Dr. Forehand her:

![Diagram of a boat with clouds above it.](image)
It is a web-based communication tool
- Patient centric
- Patient controlled

Educate and empower survivors
Enable providers to help survivors
Survivor Care Outside Survivor Clinic

• Most survivors will need to transition to adult-based care

• Primary care providers are often not
  – knowledgeable about survivor healthcare issues
  – comfortable providing care to survivors
  – providing survivor risk-based care

• Availability of critical health documents
  – <20% YA patients report having a SHP (Nathan 2008)
  – <15% PCPs report getting a SHP (Henderson 2011)
<table>
<thead>
<tr>
<th>Specialty</th>
<th>Surveys (N)</th>
<th>Response Rate</th>
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</thead>
<tbody>
<tr>
<td>Pediatric Oncologists (COG)</td>
<td>1159</td>
<td>59%</td>
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<tr>
<td>Henderson JCO 2010</td>
<td></td>
<td></td>
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<tr>
<td>Adult Oncologists</td>
<td>1249</td>
<td>41%</td>
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<tr>
<td>Henderson ASCO 2010</td>
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<td></td>
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<tr>
<td>Family Physicians (AAFP and Canada)</td>
<td>2620</td>
<td>46%</td>
</tr>
<tr>
<td>Henderson ASCO 2011</td>
<td></td>
<td></td>
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<tr>
<td>General Internists</td>
<td>1876</td>
<td>55% (surveys still being returned)</td>
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</table>
Familiarity with Long-Term Follow Up Guidelines

<table>
<thead>
<tr>
<th>Professional Group</th>
<th>Familiarity with LTFU Guidelines (1=very unfamiliar; 7=very familiar)</th>
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</thead>
<tbody>
<tr>
<td>Pediatric Oncologists (COG)</td>
<td>4.7 +/- 1.3</td>
</tr>
<tr>
<td>Henderson et al JCO 2010</td>
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<tr>
<td>Adult Oncologists (ASCO)</td>
<td>4.0 +/- 1.4</td>
</tr>
<tr>
<td>Henderson et al ASCO 2010</td>
<td></td>
</tr>
<tr>
<td>Family Physicians (AAFP and Canada)</td>
<td>2.7 +/- 1.3</td>
</tr>
<tr>
<td>Henderson et al ASCO 2011</td>
<td></td>
</tr>
<tr>
<td>General Internists (AMA)</td>
<td>1.8 +/- 1.4</td>
</tr>
<tr>
<td>Henderson et al ASCO 2012</td>
<td></td>
</tr>
</tbody>
</table>
• 29 yo female survivor of Hodgkin’s lymphoma treated at 16 years old. She received mantle radiation (25 Gy), adriamycin (150 mg/m2), and alkylators (15g/m2). She saw a physician a year ago and recently moved into your area and is here to see you for follow-up

Henderson JCO 2010
Henderson ASCO 2009, 2010
Henderson ASCO 2011
## Henderson vignette

<table>
<thead>
<tr>
<th>Late Effects</th>
<th>surveillance</th>
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<tbody>
<tr>
<td>Cardiac Late Effects</td>
<td>EKG</td>
</tr>
<tr>
<td>Anthracycline (Low Dose) Radiation</td>
<td>ECHO every 2 years</td>
</tr>
<tr>
<td>Thyroid hypothyroid/Cancer Radiation</td>
<td>Free T4 and TSH</td>
</tr>
<tr>
<td></td>
<td>Thyroid H and P</td>
</tr>
<tr>
<td>Breast Cancer Radiation</td>
<td>Mammogram yearly</td>
</tr>
<tr>
<td></td>
<td>Beginning 8 years after RT or age 25 whichever occurs last</td>
</tr>
</tbody>
</table>
Vignette - Physician Concordance with COG Long-Term Follow Up Guidelines

![Bar chart showing physician concordance with COG guidelines for different specialties and groups.](chart.png)
SHP – road map for Long-Term Follow-Up

Survivor healthcare plan

Diagnosis | Treatment | Monitoring for reoccurrence | Surveillance and treatment of late effects

~2 years off therapy

Oncologist

Survivor Clinic

Pediatrician

Adult PCP

UHC Provider
Communication Tool for Transitions

• From Pediatric to Adult Healthcare
• From Parents to Survivor

Cancer SurvivorLink™
Welcome to SurvivorLink

SurvivorLink has been designed to:

1. Increase **awareness** and **knowledge** about the life-long healthcare needs of pediatric cancer survivors
2. Increase **communication** about the specific healthcare needs of individual survivors between:
   a. Survivor and Family  
   b. Cancer Survivor Team  
   c. Primary Care Provider  
   d. Healthcare Subspecialist

On SurvivorLink, over the next three years we plan to develop portals targeting three areas of the survivor care community:

- **Provider Portal**, which will give providers access to:
  o CME educational material about survivorship  
  o Links to useful resources to assist in providing care for pediatric cancer survivors  
  o Access to your patients' Survivor Healthcare Plan* which will assist you in identifying existing medical problems in your patient, late effects they are at risk for, and recommended screening for your patient

- **Patient Portal**, which will provide access to the patient's Survivor Healthcare Plan (SHP) including:
  o Cancer Treatment Summary  
  o Individualized Late Effects Risk Profile
SurvivorLink™ – LEARN (Virtual Library)

- Quick Facts
  - Based on Provider Feedback / Focus Groups
- COG Health Links
- Continuing Education Modules - Free
- Resources
  - ACS
  - NCI
  - COG
  - CURE
  - LiveSTRONG
SurvivorLink™ – LEARN (Virtual Library)

Patient Portal – educational material

• COG Health Links
  — Many are in Spanish

• Health Insurance Information

• YA materials

• Resources
Cancer Survivorship

Since the 1970s, survival rates for childhood cancer have increased dramatically and today nearly 80 percent of children with cancer will become long-term survivors.1

It is estimated that one in every 400 young adults is a childhood cancer survivor and this number will only grow as more children survive these diseases.2 The treatments used to treat childhood cancers can damage normal tissues and cause health problems after therapy; these are called late effects. Receiving lifelong care for early detection and intervention of late effects is the best way to improve health and quality of life in childhood cancer survivors.

The Laura Armstrong Foundation (LAF) and Centers for Disease Control and Prevention (CDC) define cancer survivors as “people who have been diagnosed with cancer and those people in their lives who are affected by the diagnosis, including family members, friends, and caregivers.”3 For the purpose of long-term follow-up care, the Childhood Oncology Group recommends beginning survivor care two years after completion of chemotherapy or five years after diagnosis. Oncology follow-up and survivor care are not mutually exclusive, and a patient may still be followed regularly by his oncologist until it is no longer necessary. As survivors move away from treatment, the risk of recurrence decreases, but the risk for late effects is still present and—in some cases—increases with time. This is why lifelong monitoring is important.

The issue of cancer survivor care has been addressed on a national level recently by multiple Institute of Medicine reports and a National Action Plan for Cancer Survivorship developed by the CDC and the LAF.4 Nationally, several recommendations have been made to improve survivorship care and aid patients in the transition from cancer patient to cancer survivor. These recommendations include:

- Consider survivors a distinct phase of cancer care.
- Raise awareness about the special needs of cancer survivors.
- Provide educational opportunities to healthcare providers caring for cancer survivors.
- Develop and utilize models of coordinated interdisciplinary care.
- Generate comprehensive care summaries for each cancer survivor.
- Develop evidence-based clinical practice guidelines.
- Conduct survivor-focused research.

Childhood Cancer Survivor Study

Much of the information about childhood cancer in the survivors has been learned through the Childhood Cancer Survivor Study (CCSS). This study recruited survivors from 26 institutions diagnosed between 1970 to 1986 with leukemia, central nervous system tumors, Hodgkin’s lymphoma, non-Hodgkin’s lymphoma, Wilms’ tumor, neuroblastoma, soft-tissue sarcoma or bone tumor. The study has been pivotal in identifying medical, psychological and social problems in childhood cancer survivors as they age.5 This study began in 1993 and collected information from 14,370 survivors and 3,787 sibling controls. Now in the second phase, an additional 14,000 survivors diagnosed between the years 1987 to 1999 are actively being recruited to join the CCSS. Findings from the CCSS have led to the continued development of cancer therapy agent-based risk profiles and individualized survivorship care plans.

Neurocognitive, Behavioral and Psychological Late Effects in Childhood Cancer Survivors

Since the 1970s, survival rates for childhood cancer have increased dramatically and today nearly 80 percent of children with cancer will become long-term survivors.1

The success in treatments and increase in survival rates has led to a large number of childhood cancer survivors. It is estimated that one in every 400 young adults is a survivor of childhood cancer and this number will only grow as more children survive.2 The treatments used to treat childhood cancers can damage normal tissues and cause long-term health problems after cancer therapy. These late effects of cancer treatment can occur in all organ systems. The types of late effects a survivor is at risk for developing is dependent on the specific cancer treatment agents that were used and the risk is often proportionate to exposure dose.

Some late effects develop soon after cancer treatment and some take years to manifest. Therefore it is important for survivors to receive regular long term follow-up from healthcare providers familiar with the late effects of cancer treatment. This long-term, follow-up care is facilitated by a survivor healthcare plan which includes:

- A medical summary of cancer treatment
- A complete late effects risk profile based on cancer agent exposure
- A surveillance plan for the early detection of late effects

Survivors can be at risk for neuropsychological late effects related to their diagnosis and treatment regimen. Neuropsychological late effects include problems with:

- Behavioral functioning (neurobehavioral disorders)
- Cognitive functioning (neurocognitive disorders)
- Motor functioning (neuromotor disorders)

Patients at highest risk for neuropsychological late effects include those who received treatment damaging the brain, including brain tumors, brain surgery, cranial radiation or specific types of chemotherapy. Patients treated at a young age are also at higher risk of developing neuropsychological late effects.

Cancer diagnosis

For children diagnosed with a brain tumor, neuropsychological problems are associated with the location of the tumor, the type of tumor and the rate of tumor growth. In addition, these patients usually receive surgery which can also contribute to neuropsychological, neurocognitive or neuromotor problems.
Keeping Your Heart Healthy after Treatment for Childhood Cancer

Most childhood cancer survivors do not develop heart problems; however, certain types of cancer treatment given during childhood can sometimes result in problems with the heart. Since heart problems may occur many years after cancer treatment, it is important for childhood cancer survivors to be aware of any treatments they may have received that can affect the heart. That way, they can take steps to keep their heart healthy, including regular medical check-ups and tests to monitor heart function. And if a problem develops, it can be detected and treated early.

How does the heart work?

The heart is a muscular organ that is at the center of the body's circulatory system. The heart is responsible for pumping blood with oxygen and nutrients to body tissues. There are four chambers (two atria and two ventricles) within the heart that work together to pump blood. Valves direct the flow of blood through the heart chambers and into the blood vessels. The rhythm of heart contraction and rate of the heartbeat are coordinated by nerves that send electrical impulses to different parts of the heart. A thin membrane (pericardium) surrounds and protects the heart and anchors it within the chest.

What types of cancer treatments can cause heart problems?

The heart can be affected by certain types of chemotherapy and by radiation therapy.

- Anthracycline chemotherapy
  The anthracyclines are a type of chemotherapy used to treat many childhood cancers. This type of chemotherapy can sometimes affect the heart. Commonly used anthracyclines include:
  - Doxorubicin (Adriamycin®)
  - Daunorubicin (daunomycin, Cerubidine®)
SurvivorLink™ – STORE

• Survivor can upload in an (e) personal health record
  – Survivor healthcare plan
  – Other important letters (specialists)
  – Study (lab or other tests) results

• Providers can upload for survivors
  – Key documents/letters
SurvivorLink™ – SHARE

• Survivor can SHARE their personal health records
  – With any registered provider
  – What if the provider doesn’t know anything about SurvivorLink™ and is not registered
Provider info sheet on-
Why register for SurvivorLink™?

Dear Provider,

Your patient, a childhood cancer survivor, has registered for a new web-based resource: SurvivorLink (www.cancersurvivorlink.org). The goal of SurvivorLink is to enable better care and quality of life for childhood cancer survivors by providing a tool for communication between survivors and their providers.

SurvivorLink is a multifaceted online resource that provides:

- A repository for your patient’s health records, which you can access, enabling you to provide better care to your patient
- “QuickFacts” to provide you with a quick reference about late effects across all organ systems
- CE Modules-accredited educational material to educate healthcare providers like yourself about the special ongoing care required for childhood cancer survivors
- Links to external resources related to late effects and survivorship

SurvivorLink was developed by doctors, nurses, researchers and engineers at

- Children’s Healthcare of Atlanta
- Georgia Institute of Technology
- HIMformatics, LLC

Funding for SurvivorLink is provided by the Agency for Healthcare Research & Quality, the Lance Armstrong Foundation and the Georgia Cancer Coalition.

We encourage you to visit the website and register for SurvivorLink at www.cancersurvivorlink.org. Once registered, your patient can share their health record with you and you can begin providing optimal care for your childhood cancer survivor patient.

Sincerely,
The SurvivorLink Team
SurvivorLink™ – Security

- HIPAA compliant
- Access log
- Survivor can revoke privileges at any time

Patient Security

The table below records a log of all people and the times this record has been accessed. This is a safety feature for you. The table is in order of date with the most recent access listed first.

If there is unauthorized access of this record please Contact Us immediately.

<table>
<thead>
<tr>
<th>Date/Time</th>
<th>Person</th>
<th>IP Address</th>
<th>Comment</th>
</tr>
</thead>
</table>
Visitors from all 50 states and Washington DC
# visits
September 1, 2009 – September 1, 2013

- Visitors from 64 countries
- # visits
Survivor Controlled

• LEARN
• STORE
• SHARE
Outline

• Case

• Health of Adult Survivors of Pediatric Cancer

• What is Survivor care

• What is SurvivorLink™

• College Health and Student Survivors
Georgia Providers Invested in Survivor Care

1. GPACS- 4 Peds Onc

2. Professional Healthcare Organizations

3. College Health Network
Partnership with College Health in GA

Why College Health?
1. 1st transition to adult care
2. College Health providers are ideal partners
   - they “get” Young Adults
   - they like Young Adults
   - Engaged
   - Knowledgeable
Partnership with College Health in GA

• Partnership with 8 Universities in GA
  – access to >150,000 young adults
  – 1:530 YA is a survivor

• Test interventions to improve the success of transition
  – Capture survivors in their senior year of high school
    • Make sure they are registered on SurvivorLink
    • Make sure they have their SHP loaded
    • Help them share with registered College Health Providers
  – Make sure every College has registered providers
University Healthcare Providers as Partners in Transition of Childhood Cancer Survivors
University Health Care Providers as Partners in Transition of Childhood Cancer Survivors

Lillian R Meacham MD and Brooke Cherven, RN, MPH, Emory University; Ronald Forehand MD, University of Georgia

ACHA: College Health in Action; 53(2) October/November/December 2013
University Health Centers and Young Adult Survivors: Changes in providers’ familiarity with and practice of survivor care

Lillian R. Meacham, MD\textsuperscript{1,2}; Rebecca S. Williamson, MPH\textsuperscript{1}; Ronald L. Forehand, MD\textsuperscript{3}; Brian M. DeLoach, MD\textsuperscript{4}; Sharon R. Rabinovitz, MD\textsuperscript{5}; Michael J. Huey, MD\textsuperscript{6}; Maureen L. Olson, MD\textsuperscript{7}; Leslie Cottrell, MD\textsuperscript{8}; Paula J. Edwards, PhD\textsuperscript{9}; Brooke O. Cherven, RN, MPH\textsuperscript{1}; and Ann C. Mertens, PhD\textsuperscript{1,2}

Aims

1. Introduce concept of UHC as partners.
2. Show how SurvivorLink can be used.
   – Educate
   – Share critical documents
University of Georgia

University Health Center
UGA Performance Improvement Initiative: Establish UHC as a Partner in the Care of Childhood Cancer Survivors

UGA Student Health Providers and Aflac Cancer Survivor Program

Aims

1. Educate UGA healthcare staff about the unique needs of survivors through CME lectures and on-line educational resources.

2. Primary Care Staff will register on Cancer SurvivorLink™.

3. Identify and enroll students into a UGA cancer survivor registry.
### UGA Aim 1 - Educate Medical Clinician Staff

97% of 18 Physicians and 12 PA/NP earned ≥ 1 hour

<table>
<thead>
<tr>
<th>Title</th>
<th>Format</th>
<th>Hours</th>
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<tbody>
<tr>
<td>College Childhood Cancer Survivors in Transition: Where Do We Go From Here</td>
<td>Lecture</td>
<td>23</td>
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<tr>
<td>Barriers to Wellness &amp; Medical Transition in Adolescent &amp; Young Adult (AYA) Childhood Cancer Survivors</td>
<td>Lecture</td>
<td>26</td>
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<tr>
<td>Survivor Care 101</td>
<td>Text</td>
<td>4</td>
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<tr>
<td>Living Beyond Childhood Cancer: Survivor Healthcare</td>
<td>Video</td>
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<td>Gonadal Dysfunction in Survivors of Childhood Cancer</td>
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<td>Growth and Weight Problems After Childhood Cancer Treatment</td>
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<td>Neurocognitive, Behavioral and Psychological Late Effects in Childhood Cancer Survivors</td>
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<tr>
<td>Thyroid Problems After Childhood Cancer Treatment</td>
<td>Text</td>
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</table>

**Total Continuing Education Hours**: 71
UGA AIM 2 – Primary Care Providers Will Register on SurvivorLink™

- 83% (15/18) of PCPs registered
- 60% (18/30) medical clinicians registered
- 15 Clinicians took pre and post ed survey

<table>
<thead>
<tr>
<th>Professional Degree</th>
<th>On Staff</th>
<th>Completed Survey N=16</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor of Medicine</td>
<td>14</td>
<td>10</td>
<td>62.5%</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>4</td>
<td>3</td>
<td>18.8%</td>
</tr>
<tr>
<td>Physician Assistant</td>
<td>8</td>
<td>1</td>
<td>6.3%</td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>1</td>
<td>1</td>
<td>6.3%</td>
</tr>
<tr>
<td>Doctor of Optometry</td>
<td>2</td>
<td>1</td>
<td>6.3%</td>
</tr>
<tr>
<td><strong>Average Years Registered</strong></td>
<td></td>
<td></td>
<td><strong>1.0 ± 0.38</strong></td>
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</tbody>
</table>

Aflac Cancer and Blood Disorders Center and UHC University of Georgia
## Changes in **Familiarity** with Medical Care for Survivors

<table>
<thead>
<tr>
<th>Familiarity with Survivor Care</th>
<th>Pre-Survey (n=16)</th>
<th>Post-Survey (n=16)</th>
<th>Test Value</th>
<th>p-value</th>
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</thead>
<tbody>
<tr>
<td><strong>Average score, Mean ± SD</strong></td>
<td>1.94 ± 0.57</td>
<td>2.56 ± 0.81</td>
<td>-3.48b</td>
<td>0.003</td>
</tr>
<tr>
<td><strong>Distribution of responses, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very High</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>-2.67c</td>
<td>0.01</td>
</tr>
<tr>
<td>High</td>
<td>0 (0.0%)</td>
<td>1 (6.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>2 (12.5%)</td>
<td>9 (56.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>11 (68.8%)</td>
<td>4 (25.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Low</td>
<td>3 (18.8%)</td>
<td>2 (12.5%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Familiarity with a Survivor Healthcare Plan (SHP)

| **Average score, Mean ± SD**  | 2.38 ± 0.89      | 3.06 ± 0.85       | -2.71b     | 0.02    |
| **Distribution of responses, n (%)** |                  |                   |            |         |
| Very High                     | 0 (0.0%)         | 0 (0.0%)          | -2.30c     | 0.02    |
| High                          | 1 (6.3%)         | 5 (31.3%)         |            |         |
| Moderate                      | 7 (43.8%)        | 8 (50.0%)         |            |         |
| Low                           | 3 (18.8%)        | 2 (12.5%)         |            |         |
| Very Low                      | 3 (18.8%)        | 1 (6.3%)          |            |         |

\[a\] Average score was calculated using very low = 1, low = 2, moderate = 3, high = 4, and very high = 5.

\[b\] Paired t-test t-value; DF = 15

\[c\] Wilcoxon Rank Sum Z-value
## Changes in Provider Clinical Practice for Survivors

<table>
<thead>
<tr>
<th></th>
<th>Pre-Survey (n=16)</th>
<th>Post-Survey (n=16)</th>
<th>Z-value&lt;sup&gt;a&lt;/sup&gt;</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Provide targeted late effects surveillance, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provides late effects surveillance</td>
<td>2 (12.5%)</td>
<td>10 (62.5%)</td>
<td>-2.53</td>
<td>0.01</td>
</tr>
<tr>
<td>Does not provide late effects</td>
<td>14 (87.5%)</td>
<td>6 (37.5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>surveillance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Comfort in providing long-term follow-up survivor care, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comfortable/Very Comfortable</td>
<td>6 (37.5%)</td>
<td>6 (37.5%)</td>
<td>0.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Neutral</td>
<td>2 (12.5%)</td>
<td>7 (43.8%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Uncomfortable/Uncomfortable</td>
<td>8 (50.0%)</td>
<td>2 (12.5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Referred Patients to a Survivor Program for a SHP, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referred ≥1 patient in the last year</td>
<td>2 (12.5%)</td>
<td>10 (62.5%)</td>
<td>-2.83</td>
<td>0.01</td>
</tr>
<tr>
<td>No referrals in the last year</td>
<td>14 (87.5%)</td>
<td>6 (37.5%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup> Wilcoxon Rank Sum Z-value
# UGA AIM 3 – Identify and Enroll Students into a UGA Cancer Survivor Registry

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N</th>
<th>Age at Diagnosis (mean, yrs)</th>
<th>Time Since Diagnosis (mean, yrs)</th>
<th>Current Age (mean, yrs)</th>
<th>Cancer Diagnosed ≤21 years</th>
<th>Diagnosed before matriculation</th>
<th>Self-Reported on Entrance Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>95</td>
<td>16.9</td>
<td>9.5</td>
<td>26.4</td>
<td>71</td>
<td>65 (90.4%)</td>
<td>59 (90.8%)</td>
</tr>
<tr>
<td>Brain</td>
<td>6</td>
<td>7.0</td>
<td>16.2</td>
<td>23.2</td>
<td>6</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
</tr>
<tr>
<td>Breast</td>
<td>2</td>
<td>39.5</td>
<td>13.5</td>
<td>53.0</td>
<td>0</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Kidney</td>
<td>2</td>
<td>4.5</td>
<td>18.5</td>
<td>23.0</td>
<td>2</td>
<td>2 (100%)</td>
<td>2 (100%)</td>
</tr>
<tr>
<td>Leukemia</td>
<td>20</td>
<td>10.4</td>
<td>12.5</td>
<td>22.9</td>
<td>19</td>
<td>19 (100%)</td>
<td>18 (94.7%)</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>11</td>
<td>11.5</td>
<td>9.9</td>
<td>21.5</td>
<td>11</td>
<td>10 (90.9%)</td>
<td>10 (100%)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>24</td>
<td>19.0</td>
<td>7.1</td>
<td>26.1</td>
<td>19</td>
<td>15 (78.9%)</td>
<td>13 (86.7%)</td>
</tr>
<tr>
<td>Ovarian</td>
<td>3</td>
<td>16.3</td>
<td>10.0</td>
<td>26.3</td>
<td>2</td>
<td>2 (100%)</td>
<td>2 (100%)</td>
</tr>
<tr>
<td>Prostate</td>
<td>2</td>
<td>50.5</td>
<td>9.5</td>
<td>60.0</td>
<td>0</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>6</td>
<td>11.6</td>
<td>9.2</td>
<td>20.8</td>
<td>6</td>
<td>6 (100%)</td>
<td>5 (83.3%)</td>
</tr>
<tr>
<td>Testicular</td>
<td>7</td>
<td>21.4</td>
<td>4.6</td>
<td>26.0</td>
<td>3</td>
<td>2 (66.7%)</td>
<td>2 (100%)</td>
</tr>
<tr>
<td>Thyroid</td>
<td>7</td>
<td>25.7</td>
<td>5.1</td>
<td>30.9</td>
<td>1</td>
<td>1 (100%)</td>
<td>1 (100%)</td>
</tr>
<tr>
<td>Other*</td>
<td>5</td>
<td>25.4</td>
<td>8.6</td>
<td>34.0</td>
<td>2</td>
<td>1 (50.0%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

*Cervical (n=1), Colon (n=1), Liver (n=1), Squamous skin cell (n=1), and Uterine (n=1)
Noteworthy Outcomes of this Initiative: Patient Demographics

• The prevalence of childhood cancer survivors on campus is similar to the general population.
• There are twice as many cancer survivors on campus than patients with Type 1 DM.
• The prevalence of students with a history of skin cancer is higher than anticipated.
• Student survivors were unaware of Survivor Clinics.
• Most of our survivors do not have SHPs.
• Unidentified survivors among active patients.
• SurvivorLink™ useful to identify survivor clinics.
Locations of Major Cancer Treatment Centers in the South East United States

http://www.childrensoncologygroup.org/index.php/locations/
Welcome to SurvivorLink

SurvivorLink has been designed to:

1. Increase **awareness** and **knowledge** about the life-long healthcare needs of pediatric cancer survivors
2. Increase **communication** about the specific healthcare needs of individual survivors between:
   a. Survivor and Family
   b. Cancer Survivor Team
   c. Primary Care Provider
   d. Healthcare Subspecialist

On SurvivorLink, over the next three years we plan to develop portals targeting three areas of the survivor care community:

- **Provider Portal**, which will give providers access to:
  - CME educational material about survivorship
  - Links to useful resources to assist in providing care for pediatric cancer survivors
  - Access to your patients’ Survivor Healthcare Plan* which will assist you in identifying existing medical problems in your patient, late effects they are at risk for, and recommended screening for your patient

- **Patient Portal**, which will provide access to the patient’s Survivor Healthcare Plan (SHP) including:
  - Cancer Treatment Summary
  - Individualized Late Effects Risk Profile
Late Effects Directory of Services

The Late Effects Directory of Services is a listing of late effects services within the Children's Oncology Group. This information may be accessed by institution name, state, or city. It is provided to enable patients and families the ability to locate late effects services within COG member institutions.

Institution: All Institutions

State: Florida

City: Gainesville

Submit  Reset

Click here to display all Institutions
Noteworthy Outcomes of this Initiative: Clinicians

- Greater confidence about addressing cancer survivorship
- Improved knowledge about late effects
- Most clinicians are addressing cancer survivorship
  - Referring to Survivor Clinics
  - Performing surveillance labs and echocardiograms
  - Obtaining psychological counseling and/or testing
  - Referring for dental care

- EMR
  - SurvivorLink™ is embedded into our EMR and
  - is primary resource to link to care for childhood cancer survivors
An Initiative to Establish College Health as a Partner in the Care of Cancer Survivors

Ronald L Forehand MD$^1$, Rebecca S Williamson MPH$^2$, Garth S Russo MD$^1$, Sandy Pyle RN$^1$ and Lillian R Meacham MD$^{2,3}$
Recurrent Dysgerminoma

- Recurrent Dysgerminoma of R ovary
  - Dx 2006 - R oophorectomy
  - 8/2007 back pain x 2 months
  Recurrent Dysgerminoma
  High Risk malignant germ cell
  - Treated on POG 9049
    - Bleomycin, Etoposide and Cisplatin
    - She received no radiation

- Past Medical Hx
  - L oophorectomy for torsion 2001

- No survivor clinic visit
# Cancer Diagnosis and Treatment

## Diagnostic Details

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Diagnosis Date</th>
<th>Date All Therapy Complete</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recurrent Dysgerminoma</td>
<td>08/18/2007</td>
<td>11/10/2007</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Primary Site</th>
<th>Other Sites</th>
<th>Stage</th>
<th>Histology/Pathology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retroperitoneum</td>
<td>none</td>
<td>NA</td>
<td>AFP 0.832, Beta HCG 110</td>
</tr>
</tbody>
</table>

**Presenting Signs and Symptoms:** Samantha presented at 15 years old with a history of recurrent UTIs and bilateral oophorectomies at Floyd Medical Center. The first one was in 2001 for left ovarian torsion and then again in 2006 for right ovarian mass, consistent with dysgerminoma. She was referred to CHOA after two months of lower back pain.

## Cancer Treatment Overview

<table>
<thead>
<tr>
<th>chemotherapy</th>
<th>Radiation</th>
<th>Surgery</th>
<th>Hematopoietic Stem Cell Transplant</th>
<th>GVHD</th>
<th>Other Therapeutic Modality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

## Protocols

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
<th>Start Date</th>
<th>Completion Date</th>
<th>On/Off Study</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>POG 9049</td>
<td>A Study of High-Risk Malignant Germ Cell Tumors in Children - A Phase III Study</td>
<td>08/24/2007</td>
<td>11/11/2007</td>
<td>(Not on Study)</td>
<td>Tolerated therapy well, except for elevated creatinine just before 4th cycle. The 4th cycle was slightly delayed, but was given.</td>
</tr>
</tbody>
</table>

**Chemotherapy and Biologic Agents:**
- Bleomycin
- Etoposide
- Cisplatin

## Surgical History

**Past Surgical History**

- Pohg ovarian csc unifo
- bilaterally (asynchronous) oopherectomy

**Date:**
- 2001 and 2006
II. Late Effects and Risk Profile Monitoring

**Chemotherapy Late Effects and Recommended Monitoring**

**All Chemotherapy**

**Dental abnormalities:** Oral exam yearly; dental exam and cleaning every 6 months

**Bleomycin**

**Pulmonary fibrosis:** Pulmonary exam yearly. Chest x-ray PFTs (w/ DLCO & spirometry) at baseline; repeat before anesthesia and PRN.

**Cisplatin**

**Renal toxicity:** BP and UA yearly. Renal panel at baseline; repeat PRN.

**Acute myeloid leukemia/myelodysplasia:** CBC/differential yearly until 10 years after exposure.

**Dyslipidemia:** Fasting lipid profile at baseline then per standard recommendations (http://www.ahrg.gov/clinic/prevenix.htm).

**Peripheral sensory neuropathy:** Neurologic exam yearly until 2-3 years after therapy or until symptoms resolve. PT consult if symptomatic.

**Otoxicity (myeloablative doses only):** Otoscopic exam yearly. Audiogram or BAER/ABR yearly after completion of therapy for 5 years or until age 10 (whichever lasts) then every 5 years. If hearing loss test yearly or as recommended by audiologist.

**Testicular/ovarian dysfunction:** Tanner stage yearly. Females: FSH LH Estradiol at age 13 and PRN. Males: FSH LH Testosterone at age 14 and PRN. Semen analysis as requested by patient (recovery can occur 10 years from treatment).

**Etoposide (VP-16)**

**Acute myeloid leukemia/myelodysplasia:** CBC/differential yearly until 10 years after exposure.

**Cardiac Late Effects and Recommended Monitoring**

<table>
<thead>
<tr>
<th>Age @ Treatment</th>
<th>Radiation Involving the Heart</th>
<th>Anthracycline Dose (mg/m2) (Doxorubicin equivalents)</th>
<th>ECHO frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 y.o. or older</td>
<td>no</td>
<td>none</td>
<td>Na</td>
</tr>
</tbody>
</table>

**Chemotherapy Associated with Fertility Problems (Alkylators and Heavy Metals)**

<table>
<thead>
<tr>
<th>Alkylator or Heavy Metal</th>
<th>Cumulative Dose (mg/m2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bleomycin</td>
<td>60 mg/m2</td>
</tr>
<tr>
<td>Cisplatin</td>
<td>400 mg/m2</td>
</tr>
</tbody>
</table>

**Surgical Late Effects**

**Oophorectomy - bilateral**

**Hypogonadism, infertility:** Endocrinology or GYN consultation for initiation of hormonal replacement therapy starting at age 11.
Individualized Surveillance Plan
SHP – other things

- Problem list
- Current medications
- Allergies
- Past medical history
- Family history
- Past late effects surveillance

- Link to the guidelines www.survivorshipguidelines.org
Beth- Hypogonadism

• Problem List
  1. Ovarian Torsion 2001
  2. Dysgerminoma R ovary 2006
  3. Recurrent Dysgerminoma 2006
  4. Premature Ovarian Failure 2006

• She thought Estrogen would cause her to develop cancer in her “female organs”

Action
• Discussed the need for estrogen especially at her age
• Proposed various HRT options
back to Beth...

What did her PCP learn from her SHP?

- 19 page synopsis (with Executive Summary) of her cancer treatment and guide to monitor for potential late effects

- Recurrent dysgerminoma treated with
  - Bilateral oophorectomy
  - Bleomycin
  - Etoposide
  - Cisplatin

- Abnormal CXR without follow-up CT

- Surgical Menopause without HRT for 7 years
Recommendations from her SHP for PCP

- All CCS:
  - Annual psychosocial assessment
  - Annual dental exam / cleaning q6 months

- Bleomycin
  - Pulmonary Fibrosis: Annual exam; prn CXR and Spirometry

- Cisplatin
  - Renal toxicity: Annual BP and UA
  - Acute Myeloid Leukemia: CBC every 10 years
  - Periph Sen Neuropathy: Neuro exam every 2-3 years
  - Hearing Loss: Annual exam and
    Audiogram every 5 years
  - Gonadal dysfunction: FSH, LH & estradiol levels prn

- Etoposide (VP-16)
  - Acute Myeloid Leukemia: CBC every 10 years
Revised Plan

Motivational interviewing with goal setting regarding:

BMI due to CV risk

Smoking due to risk of

CV Disease; Pulmonary Fibrosis; Lung Cancer

Counseled risk of high FIO2 reactivation of pulmonary fibrosis

Encouraged adherence to HRT and

Chest CT recommendations

Scheduled follow-up visit
Every **Provider** who cares for a **Survivor** needs:

- **SHP**
  - Direct long-term follow-up

- **SurvivorLink™**
  - LEARN
  - STORE
  - SHARE

- **Key during times of transition**