



2009 Georgia Cancer Research Symposium

Needs Assessment to Facilitate Pediatric Cancer Survivorship Care through SurvivorLink

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EMORY
UNIVERSITY
SCHOOL OF
MEDICINE

Survivors of Childhood Cancer

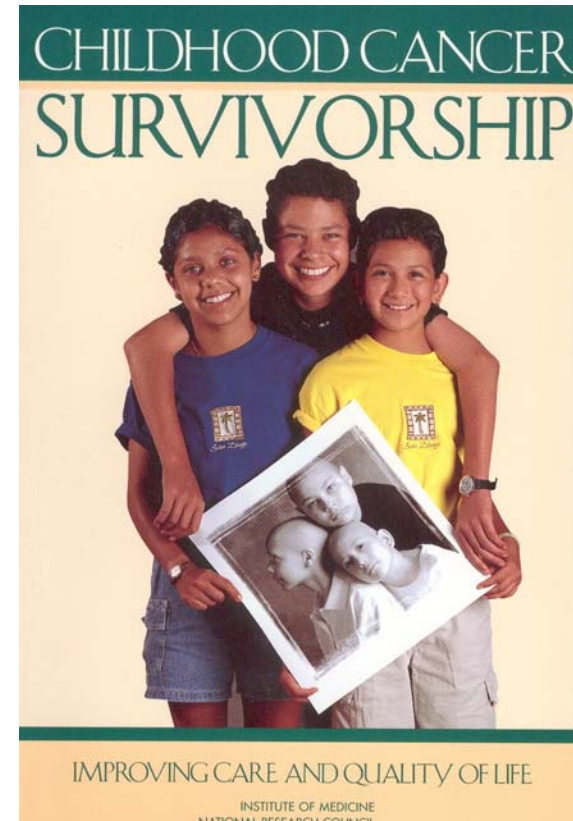
- **5 year survival rates for childhood cancer is 80%_**
- **1 in 570 between the ages of 20-34 years is a childhood cancer survivor**
- **# of life-years saved in childhood cancer is second only to breast cancer**

Selected Late Effects of Childhood Cancer

- **Growth**
- **Physical impairment**
- **Gonadal Function**
- **Fertility/Offspring**
- **Subsequent Malignancy**
- **Cardiotoxicity**
- **Pulmonary Function**
- **Neuropsychologic**
- **Psychosocial**
- **Liver Function**
- **Thyroid**
- **Gastrointestinal**

Institute of Medicine Recommendations

- **Develop evidence based clinical practice guidelines**
- **Define a minimum set of standards for follow-up care**
- **Improve awareness of late effects and implications to long-term health**
- **Improve professional education and training regarding late effects and their management**



Long-Term Follow-up Guidelines

- **Created through the Children's Oncology Group**
- **Screening and Management Guidelines**
- **Organized by treatment agent**
- **Evidence-Based**
- **Recommended by a multi-disciplinary taskforce**

Research Initiative: SurvivorLink

- **Agency for Healthcare Research and Quality (AHRQ) grant**
- **SurvivorLink - an IT system designed to support pediatric cancer survivor care in the state of Georgia**
- **Population-based initiative to provide foundation for longitudinal, innovative research**

SurvivorLink

- **Research Goals**
 - **Increase number of patients receiving recommended late effects screening**
 - **Improve knowledge of survivor care issues**
 - **Improve patient satisfaction with care**

- **Provide educational material**
 - **patients/families**
 - **health care providers**

SurvivorLink - Phase 1

- **Development of Healthcare Provider portal**
- **Target users - all healthcare professionals in Georgia**
- **Web based learning**
 - **Best practices in survivor care**
 - **CME credits**

Healthcare Provider Interviews

- **11 interviews throughout Georgia**
 - **Primary care (n=7), specialists (n=4)**

- **Results:**
 - **Moderate to very low familiarity with late effects management in survivors**
 - **High level of interest in SurvivorLink**
 - **Present survivor healthcare issues as quick facts**



Healthcare Professionals

Patients
and Their Families

Research

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



Healthcare Professionals

Search

Home

Browse by Late Effect

QuickFacts

Continuing Education

Resources

My Favorites

Welcome to SurvivorLink - Provider Portal

This portal is designed to assist healthcare professionals in providing long-term healthcare to survivors of pediatric, adolescent and young adult cancers.

This site will allow you to:

1. Browse by Late Effect Categories
2. Receive [Continuing Education](#) credit for CE modules
3. Access [Resources](#) on long-term survivor care.
4. Save [Favorites](#) pages from SurvivorLink for easy access.

1. How to 'Browse by Late Effect'

Each Late Effect category will have the following:

QuickFact

The "QuickFacts" are designed to be a quick reference for providers who need information fast. A QuickFact information sheet includes the type of health conditions you might see in that category (e.g. cardiomyopathy and arrhythmias under the Cardiac late effects category). The specific health conditions are then cross referenced in a table to the specific childhood cancer treatments that are associated with increased risk of developing those conditions. QuickFacts are available for printing in a PDF format. We will continue to add QuickFacts and periodically update existing QuickFacts.

Link to the [Children's Oncology Group Long-term Follow-up Guidelines](#)

These guidelines are arranged by cancer therapeutic agent exposure and are used by providers to identify health conditions survivors are at risk for after cancer therapy.

Health Links

[Health Links](#) are teaching handouts developed by the [Children's Oncology Group](#) and can be used as tools to educate patients and providers. Health Links are available in PDF format for printing.

Continuing Education

These continuing education text and/or video modules cover selected survivorship topics in more depth.

2. Continuing Education (CE)

SurvivorLink HCP Education QuickFact Sheets



Link to Care After Cancer

Cognitive/School

Childhood cancer survivors can be at risk for the following neurocognitive late effects:

- Functional deficits in:
 - Executive function (planning and organization)
 - Sustained attention
 - Memory (particularly visual, sequencing, temporal memory)
 - Processing speed
 - Visual motor integration
- Learning deficits in math and reading (particularly reading comprehension)
- Diminished IQ
- Behavioral change

A Survivor Health Plan (SHP) will provide you and your patient with an individualized treatment summary, risk profile and long-term surveillance plan. If your patient does not have a Survivor Health Plan, refer him/her to the appropriate survivor clinic.

Important factors in determining risk for neurocognitive late effects:

- Age of patient at time of treatment
- High dose of antimetabolite therapy
- Total dose of radiation to the head
- Combination of antimetabolites and radiation
- Premorbid or family history of learning or attention problems

Generally, patients are at highest risk of developing neurocognitive late effects if treated at a young age with cancer present in the central nervous system.

Chemotherapy Table 1	Functional Deficits	Learning Deficits	Diminished IQ	Behavioral Change
Alkylating Agents BCNU Busulfan CCNU Chlorambucil Cyclophosphamide Cytosar Ifosfamide Mechlorethamine Melphalan Procarbazine Thiotepa Dacarbazine DTIC Temozolomide				
Heavy Metals Cisplatin Carboplatin				
Antimetabolites Cytarabine Ara-C Mercaptopurine 6MP Thioguanine 6TG Methotrexate	X	X	X	X

Chemotherapy Table 2	Functional Deficits	Learning Deficits	Diminished IQ	Behavioral Change
Anthracycline Antibiotics Daunorubicin Doxorubicin Adriamycin Epirubicin Idarubicin Mitoxantrone				
Anti-tumor Antibiotics Bleomycin Daclinomycin				
Corticosteroids Dexamethasone Decadron Prednisone				
Enzymes Asparaginase				
Plant Alkaloids Vincristine Vinblastine				
Epipodophylotoxins Etoposide VP16 Teniposide VM20				

Radiation	Functional Deficits	Learning Deficits	Diminished IQ	Behavioral Change
All Radiation				
TBI	X	X	X	X
Head/Brain	X	X	X	X
Neck				
Thorax				
Abdomen				
Pelvis				
Extremity				

Surgery	Functional Deficits	Learning Deficits	Diminished IQ	Behavioral Change
Neurosurgery – Brain	X	X	X	X

For recommendations on how to screen for late effects, visit www.survivorshipguidelines.org or refer your survivor to a survivor clinic to receive a Survivor Health Plan.

Health Links – Teaching Handouts from the Children's Oncology Group

- Educational Issues

References:

Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers, and related Health Links Version 2.0. March, 2008. www.survivorshipguidelines.org.

SurvivorLink HCP Education CME Module



SurvivorLink Update
Link to Care After Cancer

Vol. 1 Issue 1 Fall 2009



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 640 young adults is a childhood cancer survivor and this number will only grow as more children survive these diseases.² The treatments used to defeat 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 Lance 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 Children's 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.^{3,4} 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 survivorship 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 survivors has been learned through the Childhood Cancer Survivor Study (CCSS). The study recruited survivors from 26 institutions diagnosed between 1970 to 1986 with leukemia, central nervous tumor, 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 3,737 sibling controls. Now in its 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.

Number of Visits to SurvivorLink

State Detail:

Georgia

Sep 18, 2009 - Nov 2, 2009

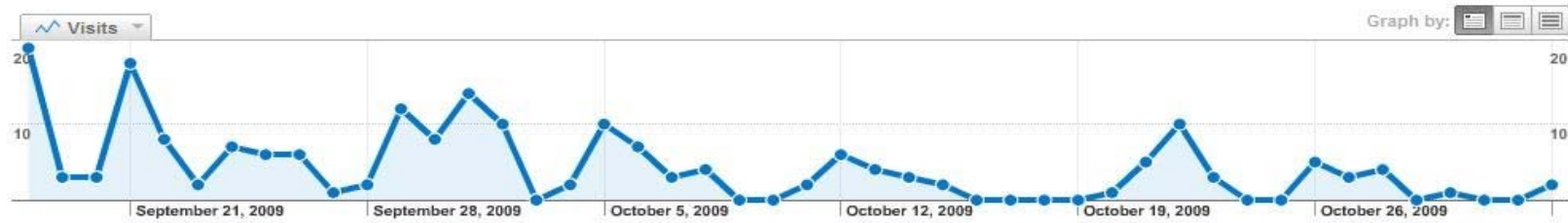


This state sent 189 visits via 13 cities

Number of Visitors to Date

New vs. Returning

Sep 18, 2009 - Nov 2, 2009



197 visits from 2 visitor types

Site Usage Goal Set 1 Views: [Grid] [List] [Table] [Full]

Visits 197 % of Site Total: 100.00%	Pages/Visit 5.74 Site Avg: 5.74 (0.00%)	Avg. Time on Site 00:05:47 Site Avg: 00:05:47 (0.00%)	% New Visits 37.56% Site Avg: 37.06% (1.37%)	Bounce Rate 24.87% Site Avg: 24.87% (0.00%)
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Visitor Type	Visits	Visits	Visitor Type contribution to total:
1. ■ Returning Visitor	123	62.44%	
2. ■ New Visitor	74	37.56%	

Filter Visitor Type: containing [] Go Go to: 1 Show rows: 25 1 - 2 of 2

SurvivorLink – Phase 2

- **Development of Patient/parent portal**

- **Serve as central repository for Survivor Healthcare Plan (SHP)**
 - **cancer treatment summary**
 - **individualized risk profile**
 - **individualized late effects screening profile**

SurvivorLink - Phase 2

- **Recruit Patient/parents and providers**
 - **300 patients at GA cancer center**
 - **100 not seen at a cancer center**
 - **100 patients from Aflac cancer survivor program**

- **Provide educational material to encourage patients to seek out a survivor consultation (to include SHP)**

Next steps for SurvivorLink

- **Utilize IT system to facilitate transfer of medical information through critical transitions of care**
- **Expand utilization to all Georgia pediatric cancer survivors**
- **Develop IT program to include materials pertinent to adult cancer survivors**

How to Utilize SurvivorLink

Healthcare Providers:

- Visit SurvivorLink site at
www.cancersurvivorlink.org
- Share website address
- Fill out registration card