# Facts and Resources: Pediatric Cancer Survivorship

## Overview

The term "cancer survivors" refers to those people who have been diagnosed with cancer and the people in their lives who are affected by the diagnosis, including family members, friends and caregivers. What it means to have survived cancer is very personal and defining “cancer survivor” may differ among individuals. Experts increasingly understand cancer as a chronic disease with life-long implications for care.

Advances in medical treatment over the last 35 years have led to improved outcomes for childhood cancer survivors:

- Cure rates, as measured by five-year survival, have increased to 78% (across all childhood cancers).
- Currently, there are approximately 300,000 people living in the United States who have a history of childhood cancer.

### What issues affect childhood cancer survivorship?

Young cancer survivors face a wide range of opportunities and challenges. Factors that influence an individual’s survivorship experience can include: age at time of diagnosis; type and severity of cancer and its treatment (surgery, chemotherapy, radiation) as well as treatment site; duration of survival; financial and geographic access to follow-up care; information needs; parental employment and insurance status (frequently interconnected); and cultural, spiritual, literacy and language differences.

As many as two-thirds of childhood cancer survivors encounter a medical problem or late effect related to their original cancer or its treatment. Late effects can occur months or even years after treatment has been completed. They vary widely and can be psychological, cognitive or physical.

### Specific needs of survivors that are not being well met include:

- Access to comprehensive follow-up care
- Assistance during re-entry into the school system, including accommodations for special learning needs or disabilities
- Connecting patients and their families with psychosocial services to deal with anxiety, depression, stress, and post-traumatic stress disorder
- Support for obtaining health and life insurance as they enter the working world
- Transitioning from pediatric to adult care and from oncology to generalized health care for long-term follow up
- Detailed information on their cancer treatment that can be carried with them and communicated to their current and future health providers

## How can we support and empower survivors and their families for long-term survivorship?

Some specific recommendations from the President's Cancer Panel include:

- Provide survivors post-treatment, with full documentation of the care they received, information about their risks of late effects, written recommendations for follow-up care, and guidance about resources to obtain follow-up
- Offer information about laws and regulations that may protect survivors in terms of employment, insurance, assets, and school accommodations
- Provide psychosocial assistance and support during and after treatment for survivors, families and caregivers
- Give patients information about the risks of infertility related to various treatments and options for preserving their ability to have children prior to treatment
- Help family members and other caregivers with better training and support

## How can systemic changes help cancer survivors?

***Medical Information:*** Detailed information about a patient's diagnosis and treatment history needs to be centralized and readily available to patients, caregivers, and any physician providing care. Primary care physicians and specialists need greater awareness of potential late effects, and resources for timely referrals. Stronger linkages between cancer specialists and primary care physicians must be established.

***Guidelines for Care:*** Guidelines and specialized clinics for follow-up care can help promote survivorship. Efforts should be made to consider and address the needs of survivors in all state cancer plans. The Centers for Disease Control and Prevention (CDC), National Cancer Institute (NCI), American Cancer Society (ACS) and other federal and national organizations are dedicated to working with state, territory and tribal coalitions to establish and implement comprehensive cancer control plans and activities to support these needs.

***Economic-Employment-Insurance Status:*** Cancer can have a profound impact on the patient's and family's economic and employment status, which in turn influences health insurance, access to care, and survivorship. With job loss or changes, survivors (or family caregivers) may lose access to health and life insurance. This employment-insurance interaction needs to be understood and addressed, at all stages of survivorship.

***School Re-entry:*** Returning to school after a cancer diagnosis – school re-entry – can be one of the most difficult and most important milestones for a child with cancer. School can provide a refuge and a sense of normalcy for childhood cancer survivors. Academic programs that inform families, medical and school personnel about appropriate accommodations can help children to succeed from the point of re-entry and throughout their school career.

## SPECIAL PROJECT: Survivorship and Outreach for A LION IN THE HOUSE

**SurvivorAlert! Project,** www.survivoralert.org
The Centers for Disease Control and Prevention (CDC) is supporting outreach for A LION IN THE HOUSE with an initiative to raise awareness about the challenges facing young adult survivors of cancer. Immediately following the broadcast of A LION IN THE HOUSE, special events for survivors, their friends and families will be hosted in up to 30 cities across the country. Get involved: contact Amy Steinkuhl, amy@kcp.uky.edu

## Resources for Pediatric Cancer Survivorship

**Indicates organizations serving as national partners or advisors to the ITVS Community Engagement Campaign for* A LION IN THE HOUSE

**Alliance for Childhood Cancer,** http://www.allianceforchildhoodcancer.org/
Alliance for Childhood Cancer provides a forum of national patient advocacy groups and medical and scientific organizations which meets regularly, shares ideas and concerns, and works collaboratively to advance research and policies to prevent cancer and improve public education and the diagnosis, treatment, supportive care and survivorship of children and adolescents with cancer.

**Beyond the Cure,** http://beyondthecure.org/
Beyond the Cure was created by The National Children's Cancer Society for survivors of childhood cancer to help them integrate the cancer experience into their new lives as survivors, successfully handle the challenges that are ahead of them and celebrate survivorship.

**Candlelighters Childhood Cancer Foundation,** http://www.candlelighters.org/
The Candlelighters Childhood Cancer Foundation national office was founded in 1970 by concerned parents of children with cancer and is committed to providing support, education and advocacy for children and adolescents with cancer, survivors of childhood/adolescent cancer, their families and the professionals who care for them.

***Centers for Disease Control and Prevention,** http://www.cdc.gov/cancer/survivorship/
The overarching goal of the Centers for Disease Control and Prevention (CDC) survivorship efforts is to create and implement along with partners, successful strategies to help the millions of people who live with, through and beyond cancer.

***Children's Cause for Cancer Advocacy,** http://www.childrenscause.org
The Children's Cause for Cancer Advocacy (CCCA) is a non-profit organization that works as a national catalyst to stimulate drug discovery and development for childhood cancers expand resources for research and treatment, and address the needs and concerns of survivors.

***CureSearch,** http://www.curesearch.org/
CureSearch unites the world's largest childhood cancer research organization, the Children's Oncology Group, and the National Childhood Cancer Foundation through a shared mission to cure childhood cancer. They believe that research is the key to cure.

**Group Loop,** http://www.grouploop.org/
Group Loop is a safe place for teens with cancer and their parents to build an online community to find support, education and hope while dealing with a cancer diagnosis.

***Lance Armstrong Foundation,** http://www.livestrong.org
The Lance Armstrong Foundation (LAF) believes that in the battle with cancer, unity is strength, knowledge is power and attitude is everything. Founded in 1997 by cancer survivor and champion cyclist Lance Armstrong, the LAF provides the practical information and tools people living with cancer need to live strong. The mission of the LAF is to inspire and empower people with cancer to live strong. They serve their mission through education, advocacy, public health and research programs.

***Leukemia & Lymphoma Society,** http://www.leukemia-lymphoma.org/
The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health organization dedicated to funding blood cancer research, education and patient services. The LLS's mission is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

***National Cancer Institute/Cancer Information Service,** http://cis.nci.nih.gov/
The National Cancer Institute (NCI) Cancer Information Service is a free, national information and education network that provides the latest and most accurate cancer information to patients, their families, the public and health professionals. By calling 1-800-4-CANCER (1-800-422-6237), individuals throughout the United States and its territories receive personalized, confidential responses to specific questions about cancer.

***National Cancer Institute/Office of Cancer Survivorship**, http://dccps.nci.nih.gov/ocs/
The mission of the Office of Cancer Survivorship (OCS) is to enhance the quality and length of survival of all persons diagnosed with cancer and to minimize or stabilize adverse effects experienced during cancer survivorship. The OCS conducts and supports research that both examines and addresses the long- and short-term physical, psychological, social and economic effects of cancer and its treatment among pediatric and adult survivors of cancer and their families.

**The National Coalition for Cancer Survivorship**, http://www.canceradvocacy.org/
The National Coalition for Cancer Survivorship is the oldest survivor-led cancer advocacy organization in the country and a highly respected authentic voice at the federal level, advocating for quality cancer care for all Americans and empowering cancer survivors.

***PADRES Contra El Cáncer,** http://iamhope.org/
PADRES Contra El Cáncer is a non-profit organization committed to improving the quality of life for Latino children with cancer and their families. It is the only Latino organization that focuses on pediatric oncology, and operates throughout the United States to provide educational resources and emotional support for pediatric cancer patients and their families from any racial or ethnic background. It began as a program funded by the American Cancer Society and has mushroomed to serve more than 3,000 families.

**SuperSibs,** http://www.supersibs.org/
The mission of SuperSibs is to honor, support and recognize brothers and sisters of children with cancer. Their services include a scholarship program, parenting resources and ‘Surprise and Delight’ services all focused on helping siblings feel valued and supported.

**The Ulman Cancer Fund for Young Adults**, http://www.ulmanfund.org/
The Ulman Cancer Fund (UCF) focuses on older adolescents and young adults. It sponsors eight support groups nationally with participants ranging in age from 15 to 35 years, including cancer patients, survivors, spouses, friends and children of people with cancer. It offers networking, peer mentoring and higher education scholarships for young adults whose lives have been impacted by cancer. UCF partners with many national and private agencies who serve cancer survivors.

## Publications and Survivorship Care Guidelines

**Institute of Medicine, Childhood Cancer Survivorship: Improving Care and Quality of Life,** http://iom.edu/CMS/28312/4931/14782.aspx
The more than two-thirds of childhood cancer survivors who experience late effects – that is complications, disabilities or other adverse outcomes – as a result of their disease, its treatment, or both, are the focus of the report *Childhood Cancer Survivorship: Improving Care and Quality of Life*, which outlines a comprehensive policy agenda that links improved health care delivery and follow-up, investments in education and training for health care providers, and expanded research to improve the long-term outlook for this growing population now exceeding 270,000 Americans.

**Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers,** http://www.survivorshipguidelines.org/
The Children’s Oncology Group *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* were developed as a collaborative effort of the Nursing Discipline and the Late Effects Committee. The purpose of these guidelines is to provide recommendations for screening and management of late effects that may potentially arise as a result of therapeutic exposures used during treatment for pediatric malignancies.

**National Action Plan for Cancer Survivorship,**
http://www.cdc.gov/cancer/survivorship/overview.htm
The Centers for Disease Control and Prevention (CDC) and the Lance Armstrong Foundation (LAF) are leading a public health effort to address the issues faced by the growing number of cancer survivors living with, through and beyond cancer. Through their collaboration *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* was developed.

**This facts and resources sheet about Pediatric Cancer Survivorship is a resource produced by the ITVS Community Engagement Campaign for A LION IN THE HOUSE, a documentary series coming to public television on PBS/Independent Lens, June 21st & 22nd, 2006.** The Campaign offers organizations, individuals and public television station partners opportunities to get involved in events that will: strengthen local care networks, educate the community, and increase local capacity to address the needs of patients and families, especially in overcoming barriers to care for underserved populations. **Learn more about what's going on in your community and how to get connected**.

For more information: http://www.itvs.org/outreach/lioninthehouse
Contact us: locsi_ferra@itvs.org