



...because kids can't fight cancer alone!

CandlelightersTM

Childhood Cancer Foundation

Fall 2005

The Quarterly Journal of the National Office

Childhood Cancer Awareness Tree Lighting Ceremony 2005

Lighting Ceremony & Reception with Guest Speakers,
Singer John Taglieri, Alex's Lemonade Stand, Hilby
the Juggler, and Toys for all children attending.

Saturday Dec.10th, 6:30 PM EST

Old Post Office Pavilion
1100 Pennsylvania Avenue, N.W.
Washington D.C. (Federal Triangle Metro Stop)

*Join the thousands of families who pay tribute to our
Nation's children with cancer by placing a **Gold Ribbon**
on the National Childhood Cancer Hero Tree, in
Honor or Memory of your child who has, or has had cancer.*



For more details on the Hero Tree Lighting Ceremony, see page 9

Ribbons can be purchased for \$5.00

Mail your check and the form below to:
Candlelighters National Office
P.O. Box 498, Kensington MD 20895-0498

Ribbons can also be purchased on-line at
the National website:
www.candlelighters.org/tree

Personal tributes can be added via the web

Child's Name as you wish it on Gold Ribbon:

Age _____ State _____

Please check one of the following:

_____ In Memory Of

_____ In Honor Of

Please check if you plan on attending lighting:

_____ Yes, we will be attending

_____ Number of children attending

_____ Number of adults attending

Phone No. () _____

_____ Check if you would like your
child's ribbon mailed back to you
after the tree is taken down.

Name: _____

Address: _____



The Problem of Pain in Childhood Cancer Survivors

by Dr. Lonnie Zeltzer & Linda Goettina Zame

What is pain?

This might seem like an unusual question to ask since everyone has experienced pain at one time or another. However, an understanding of pain can help you distinguish between pain that you can take care of, and pain that needs to be evaluated and treated by a doctor. Pain is a complex system of signals that carry messages up to the brain (*pain transmission system*), and down from the brain (*pain inhibitory system*) to turn off or reduce the amount of pain. Most importantly, it is in the brain itself where pain perception takes place. There are certain areas in the brain that are responsible for our experience of pain. One part of the cortex, or outer layer of the brain, is responsible for the sensory part of pain. Specifically, this part tells us how much pain we are having, what it feels like, and what part of the body it is coming from. There is another part of the cortex where the perception of “suffering” takes place. This is called the *affective pain perception* area. An illustration of how these are different is seen in the example of when a patient receives morphine after a surgery. While the sensation of pain may be reduced (“I feel less pain”), the suffering is reduced to a greater extent (“I don’t care”). Thus, there are three key concepts about pain: 1) an individual’s perception of pain takes place in the brain, 2) there is a **sensory** and a **suffering** dimension of pain perception; and 3) pain is caused by an imbalance in the ‘pain- to- brain’ and ‘brain-to-pain’ neural systems, as well as in the brain’s pain perception areas.

What makes pain a problem?

When faced with a situation of experiencing acute pain, our pain transmission (pain to brain) and pain control (brain to pain) systems work in balance. Remember the time that you accidentally closed the door on your finger. First it hurt a whole lot (pain transmission). You quickly experienced the pain and noted that the pain was in your finger

(sensory pain perception) and were bothered by it (affective pain perception). Eventually, the pain went away (pain control). The pain mechanism worked in balance to reduce and eliminate the pain. **Chronic or ongoing pain occurs when the pain system is out of balance.** This “dysregulation” can come from many causes. Persistently tense muscles in a certain part of the body, such as the lower back or neck and shoulders, can stimulate sensory nerves from those areas of the body. Hypersensitive areas can develop in those muscles (called “tender points”) and you can feel a sensation of pain when you press on them. These tender points are hallmarks of “myofascial” or musculoskeletal pain. Children or adolescents treated for osteosarcoma or other sarcomas who have had spinal changes resulting from radiation to the spine might experience postural distress on muscles. An imbalance in a child or teen’s stance that results from one leg being shorter than the other after a limb salvage procedure for bone cancer can also cause postural distress on muscles over time, and especially as the child grows. Such chronic strain on certain muscles can cause chronic myofascial pain to develop. This may be experienced as low back pain, or headaches related to chronic strain on the neck and head muscles. Arthritis can develop as a late-effect of spinal radiation or pelvic radiation. Radiated skin can also become hypersensitive long-term. This is called “neuropathic pain.” The sensory nerves in the radiated area of the skin get “turned on” and become more painful when even lightly touched.

There are other types of pain that can develop without an ongoing obvious cause. One example is phantom limb pain after an amputation. Another is called “complex regional pain syndrome type 1” or CRPS. In CRPS a part of the body becomes hypersensitive and painful, often even to light touch, or even wind or water. In these cases, the pain system gets “turned on” so that there is an

increased activity in the brain’s pain perception, and the pain “turn down” system starts working less and less efficiently and effectively. If pain continues without being effectively turned off or treated, there are neural circuits in the brain called “neural modules” that can keep the pain going. Thus, the usual balance in the body’s pain system does not work properly. Similarly, ongoing belly pain, often associated with diarrhea or constipation, or both, and/or nausea and flatulence (lots of gas), is another example of this sensory system dysregulation. In this case it is a dysregulation in the brain to the gut nervous system, called “irritable bowel syndrome.” It is important that the cause of pain is evaluated. Often, the way to treat pain is to rebalance the system. Thus, the goal of pain **evaluation** is to determine the factors that keep the system out of balance, and keep pain perception areas “turned on.” The **goal of treatment is to rebalance the pain system and turn down hyperactivity in the pain perception areas of the brain**, especially the area of pain suffering.

Who is at risk for the development of chronic pain?

The Childhood Cancer Survivor Study, comprising the largest number of survivors of childhood cancer in North America and a large group of their siblings, found that, while the majority of cancer survivors do not have chronic pain, there are certain groups of survivors that are more likely to have pain. These are survivors of bone tumors (osteosarcoma, Ewing’s sarcoma), other solid tumors, and Hodgkin disease. The “why” is unknown, although speculation suggests that after-effects of body radiation and the effect that this has on a growing musculoskeletal system may play a role. Headaches were also found to be more prevalent in survivors of child and adolescent cancer than in their siblings, although migraines were found to not be more common.

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The Problem of Pain continued...

How to know what kind of pain you have?

Most pain is treatable, and almost all pain and suffering can be reduced to some extent. If you are a survivor of childhood or adolescent cancer and have chronic pain, you do not need to “learn to live with it!” If your physician tells you that, then ask for a referral to see a pain specialist if one is available. I would also encourage you to read more about the different treatments for chronic pain. One source of information is: “Conquering Your Child’s Chronic Pain: A pediatrician’s Guide to Developing a Normal Childhood” by Lonnie K. Zeltzer MD, and Christina B. Schlank (HarperCollins, 2005). This resource describes all types of pain, as well as mind-body ways of treating pain, much of which can be done without a physician. As discussed above, to get the proper treatment for pain, it is important to understand the most likely reason(s) for the pain. For example, sometimes headaches can be signs of increased intracranial pressure related to a blocked shunt, to tumor growth, to a new tumor in the brain, to head and neck muscle spasm, or just to the central pain perception area being “turned on.” Structural and common reasons for the pain will be associated with other clinical signs that can be determined on an examination (e.g. abnormal neurological findings, tender points in the muscles, hypersensitive skin by the head). If no specific likely reason is found for the pain, this does not mean that it is “stress” or the pain is “not real” (often called “non-organic”). Rather, the pain is real and the reason for the pain is related to a nerve signaling imbalance or neural “turn-on,” including pain perception areas in the brain.

The symptoms being experienced can also be a clue to the cause of the pain. Neuropathic pain tends to be burning, sharp, stinging, shooting, stabbing. Hollow organ pain (e.g. ureter as in renal stones, uterus, intestines) tends to be crampy in waves. Muscle and bone

pain tends to be experienced as a deep aching pain. Headaches that are myofascial tend to feel achy with the head feeling squeezed or as if it is under pressure (which if in the forehead or cheeks could be a sign of sinus infection).

Locating the source of pain can sometimes be difficult because the pain which is being felt in one area of the body is actually coming from another area of the body because of the sensory nerve connections. This is called ‘referred pain.’ Examples include hip joint arthritis felt as deep aching pain in the lower thigh above the knee; diaphragm irritation at the base of the lungs felt as sharp pain in the shoulders; pain in the heart related to insufficient blood supply to the heart muscles is felt as shooting pain down the left arm; nerve outlet constriction pain, such as in the lower back is often felt as sciatica or sharp pain down the leg, etc.

How to treat your pain: a mind-body approach to treatment

The approach to most chronic pain involves some active effort on your part in order to receive the best and most long-term gains. The mind and body are connected and our memories, emotions, thoughts, and actions can affect our pain—both positively and negatively. First, it is important to figure out your primary mood. Do you feel depressed much of the time? Depression can be associated with poor appetite, sleep, and energy. The desire to maintain a routine or participate in new activities is low. You may feel that you are in a rut that you can’t seem to get out of. The joy in life is gone. It is important to know that chronic pain can cause depression, which in turn can make chronic pain worse. Chronic pain can reduce the production of needed chemicals (neurotransmitters) that impact mood. In turn, lower levels of those neurotransmitters can reduce the efficiency of the body’s pain control system, making it more difficult to turn down pain signals.

Similarly, anxiety or stress can increase the volume of pain transmission, causing more pain. Acute, intermittent pain can become a source of anxiety while waiting for the next pain episode. Since anxiety disorders are rather common, many people do not know that by reducing anxiety they can also reduce their pain.

There are medications and complementary therapies that can be used to reduce depression, anxiety, and/or chronic pain. Medications should be prescribed by a physician and monitored for their effectiveness as well as side-effects. It is important to report both negative and positive effects to your doctor. It is important to remember that many herbal and other “natural” products can change the metabolism of medications and so all products, whether prescribed or not, should be discussed with the doctor. Complementary therapies for pain include common approaches such as physical therapy, exercise (especially swimming), and good sleep, as well as the less common ones which includes acupuncture, hypnotherapy, Iyengar yoga, biofeedback, craniosacral massage, regular massage, Reiki and other forms of energy therapy, art therapy, music therapy, and other therapies that create homeostasis and balance in your nervous system. Psychotherapy can come in different forms and be valuable if you have depression and/or anxiety. Sometimes the cancer experience can be associated with symptoms of post-traumatic stress disorder (PTSD) in which the central arousal system is chronically “turned on,” keeping pain signals on high volume, lowering the “alert system set-point,” creating sleep difficulties, as well as other problems. Psychological interventions can be very helpful for many survivors with chronic pain to help learn specific coping skills to be able to function, while the pain begins to diminish. The goal in the treatment of chronic pain is to initially promote increased

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The Problem with Pain continued...

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physical function, followed by a decrease in the intensity of the pain, and subsequent elimination of all pain over time.

Summary

Pain is caused by an imbalance in the pain transmission and control systems of the body. All pain perception (the feeling part and suffering caused by pain) takes place in the brain. The type of pain and location give clues as to what might be causing the pain. Pain that doesn't improve on its own will let you know when to get help.

Remember that all pain can be made worse by stress and lack of sleep, so it is important to find ways to reduce stress and improve sleep patterns. All pain involves both the mind and the body. How we think and feel physically influences pain signals. Treatment for pain can include medication, but should also include at least one physical form of therapy, (e.g. Iyengar yoga, physical therapy, massage, exercise) as well as psychological therapy (e.g. relaxation and breathing techniques, biofeedback, hypnotherapy, psychotherapy). It is the combination of both mind and body treatments that can rebalance the pain neural system and reduce the brain's pain perception to control pain and suffering.

Dr. Zeltzer is a professor of pediatrics, Anesthesiology, Psychiatry and Biobehavioral Sciences at the David Geffen School of Medicine, UCLA; Director of the Pediatric Pain program at UCLA Mattel Children's Hospital and is the Associate Director of the Patients and Survivors Program in the UCLA Jonsson Comprehensive Cancer Center.

Linda Goettina (Zame) D.M.H. is a 30+ year survivor of Hodgkin's disease with a doctorate in mental health from UCSF. In 1998 she founded the first internet discussion group for long term cancer survivors—now with over 400 members. She went on to found Ped-Onc survivors and 4YOUth. In 2005 she was elected to the National Candlelighters board of directors. She has been active as a health advocate for survivors since 1998.

Stories from Adult and Child Survivors Who Have Suffered with Chronic Pain

At least once a month someone new signs onto the childhood cancer long-term survivors' discussion listserv and in their brief introductory letter they usually write something about chronic pain or discomfort. One of the interesting things is they don't call it pain and they frequently don't associate it to prior treatment. There are many euphemisms applied to this state, things like "I have a delicate stomach, or a weak neck, or my body is lopsided." The euphemisms describe the state but not necessarily the visceral experience. After many years of adjusting to discomfort and chronic pain, many survivors of childhood or adolescent cancer no longer recognize their experience as pain, although this often limits their pleasure and enjoyment of life.

These pain states may have developed during treatment or not long after treatment was finished, or even many years later. But as everyone was most concerned with eliminating the cancer, things like pain were and are frequently discounted, and if the pain develops long after treatment has finished, many survivors and physicians do not have the skills or knowledge necessary to associate the pain with past cancer treatment(s). More than one survivor who has tried to describe their pain state has been met with the response "but your cancer was cured, you should be so grateful." Or the survivor feels they are complaining unnecessarily about a treatment that saved his or her life. All of this contributes to a situation where physician and survivor live in a state of denial about chronic pain in survivors, and survivors are often under-treated for chronic pain.

Margie is a typical example. She was treated for Hodgkin's Disease in her late teens back in the 1970's. Her treatment, state of the art at the time, included high dose radiation to an area described as the Mantle, which includes a field that extends from the base of the skull down to the top of the diaphragm. Margie, like lots of other HD survivors treated with this protocol, has a very thin neck. When she first signed onto the list she described the embarrassment she felt about her weak neck, too weak to lift from a hair salon shampoo basin unassisted. Margie can't sit for long in a typical dining room chair because in order to be comfortable she needs a back rest that holds her upper back and neck. At home she finds she is most comfortable in her lounge chair with a heating pad draped over the back, but this does not take care of all the pain she has. And although Margie makes great adjustments and accommodations for her neck and upper back, she never thought to call this chronic pain or to seek help for it.

When Margie assessed her life, she realized that chronic pain was shaping what she did and how she did it. She was reluctant to accept dinner invitations because of the pain associated with sitting in a straight backed chair; she realized her life was more and more about accommodating pain than living and enjoying. The search for help was long and difficult, as it is for many survivors. Her first questions about the state of her neck and back were met with flat denials. And finally when she did find a physician who admitted there was muscle atrophy, this physician did not refer Margie to a pain specialist. It was only after the help and support of other survivors that Margie finally made contact with a pain specialist who began to work with her.

Margie's case is not unusual. The long term survivor of child and adolescent cancer faces many types of pain related to prior treatment. Although most of

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ALTE03N1 Study: Key Adverse Events after Childhood Cancer

Incredible progress has been made in curing childhood cancer. With all this success has come the awareness that childhood cancer treatment may lead to complications in some patients. These late-occurring complications include heart attack, congestive heart failure (a damaged heart that is unable to circulate blood efficiently), avascular necrosis (poor blood supply to an area of the bone that causes permanent bone damage), stroke (blood flow to the brain is interrupted), or a second cancer.

Certain individuals may be at a higher risk for developing these late-occurring complications because of:

- genetic (or inherited) factors;
- cancer treatment;
- a combination of genetics and treatment; or
- a cause not understood at this time.

The goal of this study is to identify patients who are more likely to develop a late-occurring complication(s). If we know who is at a greater risk of developing a late-occurring complication(s), then we can observe those patients more closely, in order to prevent the complication from occurring or to find the complication early.

The specific goals of this study are:

- **to look at how late-occurring complications develop among patients going through treatment for childhood cancer;**
- **to see how late-occurring complications relate to the type of cancer, stage of cancer and treatment; and**
- **to compare cancer patients who have a late-occurring complication(s) to cancer patients who do not have a late-occurring complication(s)**

(but have the same diagnosis) in order to see if certain individuals, cancer treatment(s), or genes (the physical unit that carries characteristics from parent to child) are related to an increased risk of getting a late-occurring complication(s).

Participants will be asked to provide a biological sample. Most participants will be asked to provide 8.5 ml (about 2 teaspoons) of blood. Patients who have been previously treated with a non-autologous hematopoietic cell transplant (received cord blood, stem cells, or marrow from someone other than themselves), and patients who are unable or unwilling to give blood, will be asked to provide a sample of their cheek cells (by rinsing with a mouthwash). If you are unable to have blood drawn at your hospital/clinic you also have the option of having blood drawn at your home by a residential blood draw company.

Participants will also be asked to complete a brief health status and family history questionnaire.

Who can be in this study?

This study is for patients who meet the following inclusion criteria:

1. Diagnosis of primary cancer at age 21 or younger, irrespective of current age.
2. Development of one of the following key adverse events:
 - Congestive heart failure (CHF)
 - Myocardial infarction (MI)
 - Ischemic stroke (IS)
 - Avascular necrosis (AVN)
 - Subsequent malignant neoplasm (SMN)
3. Have been in contact with one of the participating institutions listed below within the last two years.

Why is this study important?

The results of this study will be used to learn why some individuals develop late-occurring complications following childhood cancer treatment and this may allow doctors in the future to identify individuals who may be at high risk of developing complications and to modify childhood cancer therapy in order to prevent these complications from occurring.

For more detailed information about this study please contact the Study Chair.

Smita Bhatia, MD, MPH

Director, Epidemiology and Outcomes Research
Division of Pediatrics
City of Hope Comprehensive Cancer Center
Ph: (626) 256-HOPE (4673) ext. 62147

For a detailed listing of the institutions participating in this study, see the following page.

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It's Okay, Little Prince

It's okay, Little Prince,
I want to go home too.
I can see it in your eyes,
I can hear it in your cries,
Can you see it in me too?
It's okay Little Prince,
I want to be home, too.
I can sense it in your mind,
I can feel it in your heart-so-kind,
Can you sense it in me, too?
It's okay, Little Prince,
I want to feel home, too.
But for now, I'll help you cope,
And for now, I'll give you hope,
Will you help me out too?

Mattie J. T. Stepanek, July 2001
From Hope Through Heartsongs
Reprinted with permission by
Hyperion Books

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those with chronic pain were treated with radiation, there are other survivors who have neuropathies (nerve pain) associated most frequently with chemotherapy agents like Vincristine. Although the nerve pain associated with Vincristine usually disappears over time there are some survivors who don't return to baseline and even a few who many years after treatment once again find themselves with neuropathies associated with prior treatment. These burning, tingling, even throbbing sensations can range from mildly irritating to incapacitating. Mark is a long term survivor who had Vincristine as part of his protocol. At the time of treatment he was 15 and during treatment he knew that some of the problems he had, like foot drop, were caused by his chemotherapy

drugs. Yet, when he developed burning throbbing pains in his feet at age 35, he did not associate this new problem with prior treatment. Again, like many survivors his attitude initially was one of stoicism—this was something to be borne rather than diagnosed and treated. Only when his problem threatened his livelihood, as he found it harder and harder to sit at his desk to work, did he seek help and, like Margie, found that seeking help was a long and roundabout and frequently frustrating experience. Eventually Mark found someone who recognized his foot problem for what it was and, with a combination of medications, he has found relief.

There are many more stories like Mark and Margie that elaborate and illustrate the many points Dr. Zeltzer makes in

this essay. Chronic pain does exist in long term survivors of childhood cancer. There are many causes of this pain and all treatment protocols for childhood cancer potentially can produce pain either during treatment or many years later. Chronic pain is under recognized by both survivors and physician and under treated. Survivors don't have to 'bear their pain' and Dr. Zeltzer's article here and her book offer many helpful ideas about intervention and treatment, comprehensively assessing and treating the pain of long term survivors. Survivors don't have to accept chronic pain as the price of survival. As Dr. Zeltzer so compassionately illustrates, there are ways to intervene and help.

by Linda Goettina (Zame)

Adverse Events after Childhood Cancer Study *continued ...*

Continued from page 5**Participating institutions:**

Advocate Hope Children's Hosp.
All Children's Hosp.
Allan Blair Mem Clinic
B.C.'s Children's Hospital
Baptist Children's Hospital
Baylor College of Medicine
Brooklyn Hospital Center
Broward General Medical Center
C.S. Mott Children's Hospital
Cabell Huntington Hospital
Cancer Research Ctr. of Hawaii
CancerCare Manitoba
Carolinas Med. Ctr.
Cedars-Sinai Medical Ctr.
Children's East Ontario
Child Hosp. Greenville System
Child Hosp. Michigan
Children's Memorial Hosp. (Chicago)
Children's Atlanta, Emory Univ.
Children's Hosp. & Reg. Med. Ctr.
Childrens Hosp. Columbus
Childrens Hosp. King's Daughters
Childrens Hosp. Med. Ctr. Akron, OH
Childrens Hosp. Oakland
Childrens Hosp. of L.A.
Childrens Hosp. of Philadelphia
Childrens Hosp. Cincinnati
Childrens Hospital & Clinics
Children's Hospital Pittsburgh
Children's Hospital San Diego
Children's Med. Ctr. Dayton
Childrens Mercy Cancer Center
Childrens National Med. Ctr. DC
City of Hope National Med. Ctr.
Columbia Presbyterian College
Connecticut Children's Med. Ctr.
Dakota Midwest Cancer Institute

Dana-Farber Cancer Institute
DeVos Children's Hospital
Driscoll Children's Hospital
East Tennessee Children's
Eastern Maine
Emanuel Hospital
Hackensack Med Ctr.
Hosp. Sick Children
Hurley Medical Ctr.
Indiana University
Inova Fairfax Hospital
Kaiser Foundation Research Inst.
Kalamazoo Ctr. for Med. Studies
Kingston General Hospital
Kosair Childrens Hospital
Lee Memorial Health System
Lutheran Gen. Children's Med. Ctr.
M. U. S. Carolina
M.D. Anderson Cancer Ctr.
Maimonides Medical Center
Mayo Clinic and Foundation
McGill Univ. Health Ctr.
McMaster University
Medical Center of Delaware
Memorial Sloan Kettering
MeritCare Medical Group
Miami Children's Hosp.
Michigan State University
Midwest Children's Cancer Ctr.
Nemours/Jacksonville
Nevada Cancer Res Fdn. CCOP
New York Medical College
Newark Beth Israel Medical Ctr.
Oklahoma University
Princess Margaret Hosp.
Rainbow Babies Hospital
Roanoke Valley
Roswell Park Cancer Institute
Royal Children's Hosp Brisbane
Sacred Heart Hosp.
Saint Barnabas Medical Center

Saskatoon Cancer Center
Scott & White Memorial Hosp.
Southern California Permanente
South Carolina Cancer Center
Southwest Texas Methodist Hosp.
SPOG Geneva
St. John Hosp.
St. Jude Children's Research Hosp.
St. Jude Midwest
St. Mary's Hosp.
St. Vincent Children's Indiana
St. Vincent Hospital Wisconsin
Stanford University Med. Ctr.
Stollery Children's Hospital
SUNY Stony Brook
SUNY Upstate Medical Univ.
Tampa Children's Hospital
Texas Tech UHSC - Amarillo
Tulane Univ. Med Ctr.
U. of Alabama
U. of Arkansas
U. of Florida
U. of Kansas
U. of Miss Med. Ctr.
U. of New Mexico
UMDNJ/RWJ The Cancer Inst. NJ
Univ. of Minnesota Cancer Ctr.
Univ. of Missouri - Columbia
University of Iowa Hosp
University of North Carolina
University of Wisconsin
UT Southwestern Medical Center
UT/San Antonio
Vanderbilt Children's Hospital
Wake Forest Univ. School Med.
Washington Univ.
Winthrop University Hospital
Women's & Children's Adelaide
WV Univ. Charleston
Yale University

World Cancer Day: Feb. 4, 2006

This year marks the launch of the **UICC World Cancer Campaign** focused on childhood cancer. (www.uicc.org). The World Cancer Campaign calls for an invincible alliance between researchers, healthcare professionals, patients, government, industry and media, to fight cancer and its greatest allies which are fear, ignorance and complacency. The World Cancer Campaign theme for 2006 will be "**My Child Matters**" (www.mychildmatters.org). Focused on the international impact of childhood cancer, the campaign consists of three main components: support for research initiatives to reduce childhood cancer mortality and morbidity in developing countries; a comprehensive state-of-the-art report on childhood cancers which will be made available to the general public on **World Cancer Day, 4 February 2006**; and a worldwide mobilization and awareness campaign, to highlight the effects of childhood cancers on children and their families.



Each year, more than 160,000 children world-wide are diagnosed with cancer and approximately 90,000 will die of their disease. While cure rates for many childhood cancers have reached approximately 75% in the US, more than half of all children diagnosed with cancer in developing countries will die of their disease. HIV/AIDS remains a critical priority for the

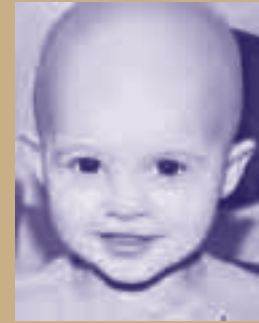
health of children in sub-Saharan Africa, but cancer is emerging as a major cause of childhood death in Asia, Central and South America, northwest Africa and the Middle East, where fewer children are now dying from preventable infectious diseases.

While many childhood cancers are now being treated successfully in the US, cancer remains the number one disease killer of America's children as well. Children diagnosed with AML, neuroblastoma IV, brainstem gliomas, and metastatic bone cancers still face a poor prognosis. Those children who do survive are often faced with life-long late-effects of treatment. Research has shown that two-thirds of childhood cancer survivors face late-effects from their disease. Of those, one quarter are classified as severe or life-threatening.

In support of the World Cancer Awareness Campaign, Candlelighters is proud to announce the **February 4th, 2006 website release of a photo essay** focused on the impact of childhood cancer in the United States. The photos will be the work of professional photographers **Jed Share** (www.jedshare.com) and **Trevor Romain** (www.trevorromain.com). Jed Share's work has taken him to more than 80 countries and has included works for JP Morgan Chase, SONY, Motorola, Mitsubishi, Microsoft, Mercedes Benz, and others. Recognized as one of the GREAT photographers in the world, Jed's photos have won him international acclaim, and have been exhibited internationally in shows sponsored by Kodak, Fujifilm, and others. His photography has been used for best-selling book covers, billboards, magazines and virtually all forms of print. Trevor Romain has written over 30 books and is recognized for his inspirational writings, brilliant illustrations, as well as incredible photography. His personal mission in life is to inspire kids to meet life's challenges with a smile. Known as 'Dr. Mischief,' Trevor is a regular on children's oncology wards, where he helps cancer kids meet the challenges of their cancer treatments. Candlelighters' is honored to have both Jed and Trevor create this photo essay to build awareness of the plight of cancer children in America.

Please mark your calendars now and invite your friends, family, colleagues, your child's oncology team, and Members of Congress to visit Candlelighters' website on World Cancer Day, Feb. 4th 2006 to view the professional photo essay of America's children with cancer. Help spread the word that childhood cancer remains the number one disease killer of America's children too!

...BECAUSE
KIDS GET
CANCER
TOO!



Candlelighters



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Cancer
Foundation**

Helping Children with
Cancer Since 1970

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Campaign
Donation!



Free Child Cancer Books

Presented in Partnership with the Lance Armstrong Foundation, Candlelighters continues to provide copies of the following childhood cancer books to families in financial need. Families may choose **one** of the following books that best applies to your child's cancer diagnosis and send the request to: Candlelighters Childhood Cancer Foundation, P.O. Box 498, Kensington MD 20895-0498; or fax to 301-962-3521

- ***Childhood Leukemia: A Guide for Families, Friends, and Caregivers***, 2nd ed., Nancy Keene.
- ***Childhood Cancer: A Parent's Guide to Solid Tumor Cancers***, Janes-Hodder & Keene.
- ***Childhood Brain & Spinal cord Tumors: A Guide for Families, Friends, and Caregivers***. Shiminski-Mahar, Cullen, Sansalone.
- ***Childhood Cancer Survivors: A Practical Guide to Your Future***. Keene, Hobbie, Ruccione.

THANKS to the LANCE ARMSTRONG FOUNDATION for their financial support of this important program!



Calling all TEENS!

Candlelighters Childhood Cancer Foundation is in the process of publishing a self-help book for Teens with Cancer. If you would like to share YOUR perspective on this cancer journey with the possibility that it will be published in an upcoming book, then please send to Teen Book, CCCF, 3910 Warner St. Kensington MD 20895.

We are looking for personal stories about thoughts on treatment, treatment tips, thoughts on traveling to treatment, stories of hope, stories of comfort; stories of how you made this work while engaging in the busy life of a teen. We'd also like to hear stories of what DIDN'T work, what bothered you the most, and how you would like to see things changed too! Remember to include your contact information in case we need to reach you!

Looking forward to sharing your journey with other teens!

My Life Went On

I was only four I didn't understand what they had said,
I couldn't tell exactly but I knew it was bad.

They couldn't hold it back I guess because everyone cried,
My first thought was that someone had died.

They took me to the doctor in quite a hurry,
I didn't know what was wrong but I was told not to worry.

The doctor and my parents told me that I was very ill,
And would have to stay in the hospital.

Doctors, chemo, and shots, I was scared to death,
I was crying so hard I couldn't catch my breath.

I told my Mom I'd be her guardian angel when I died,
I didn't mean to hurt her but I made her cry.

The days went on just like any other,
Except for the fact that each day got tougher.

One morning I got up out of bed,
Picked up my hand and touched my head,

Was going to touch what I thought was there,
That's when I realized I had no hair.

I took the hurt and I took the pain,
Because without the pain, there would be no gain.

A 40% chance of dying is what the doctor told my family,
My parents were crying as they held on to me.

They wouldn't let me go, it wasn't an option,
So we had to proceed with caution.

The next two years were the worst of my life,
The next two years were my biggest strife.

Getting shots and taking pills all became so natural,
But that's not how it's suppose to be for a 4 year old.

Even though the years they felt much longer,
Those two years are what made me stronger.

It was Easter morning when they told me it was gone,
And just like always **My Life Went On.**

By Jenni Hoffmann, diagnosed at age 4 with ALL.
Now 14 years of age, in grade 8 and doing well.

Hero Tree Lighting Ceremony *continued...*

The annual lighting of the National Childhood Cancer Hero Tree has become the largest awareness event in the country. We welcome families and friends of children with cancer to join us for this year's lighting event. In addition to this year's guest speaker, we are excited to inform you that this year's event will include **Alex's Lemonade Stand**, with Alex's parents giving a brief talk and reading from their book, entertainment for the children by **Hilby the Juggler** (www.hilby.org), and returning by special request - **John**

Taglieri singing Bethany's Song. Note that John will be playing at Zig's Bar in Alexandria VA, following the tree lighting for those who want to hear him. As in previous years all children attending will receive toys donated by Starbucks; a hand-made quilt for each family attending, as well as other gifts for those in attendance. Come and join the fun! Come and meet other families of children with cancer!

Help us to reach 1,000 families attending this year's event!

To register, please visit: www.candlelighters.org

Note: This year's Tree is going to be decorated on Nov. 19th. We are asking families to purchase their gold ribbons prior to that date if at all possible.

HOPE TO SEE YOU THERE!

Special thanks to Nancy Hoke for the donation of this year's original art for the 2005 Hero Tree Congressional invitations!



Poster by Nancy Hoke

Book Review

Late Effects of Childhood Cancer, Edited by W. Hamish B Wallace, MD and Daniel M. Green, MD Arnold, London 2004

With a price tag of \$200 at Amazon.com this isn't likely to be an impulse purchase. But if a survivor of child/adolescent cancer lives in a small community without good medical information and support for survivors, this book might be a life saver.

Written and arranged like a textbook, this book does a good deal to explain and explore the variety of late effects that are possibilities for survivors. Most of the chapters are a comprehensive review of body systems (cardiovascular and respiratory for example), with additional chapters on secondary cancers, quality of life, and special problems associated with bone marrow transplantation. Every chapter is written by those currently doing active research into late effects of child/adolescent cancer and each has an extensive bibliography.

The book also includes guidelines on follow-up care which are always helpful in trying to determine what tests and procedures survivors should have, and on what schedule. The index is also excellent and makes the book very user friendly and accessible. However, since this volume was intended for the medical community it is written in medical language, without thought to the lay reader. But none of it is so esoteric that it remains undecipherable. Nancy Keene's book Childhood Cancer Survivors: A Practical Guide to Your Future, (O'Reilly, 2000), is an excellent resource for both parents and survivors. The Wallace and Green textbook may either serve as a complement to Keene's book or a help to a primary care physician who has never encountered a long-term survivor.

I did purchase this book and have found it very helpful and reliable when trying to find specific information for members of our internet discussion group for survivors. It has served me and members of our group well, providing excellent and helpful information. And after more than a year of use, I have found only one glaring omission and that is information on pain. There is only one index entry for pain despite the fact that chronic pain is frequently the major problem that brings survivors to join our group. But overall this is an excellent resource for survivors who do not have access to a teaching hospital or late effects clinic and I'm sure many of the primary care physicians who have survivors in their practice would like to know about this book.

Linda Goettina (Zame) D.M.H.

FALL SALE ON LAPEL PINS AND CHARMS!

Order your gold ribbon or logo charms and lapel pins through Candlelighters webstore and have 100% of the proceeds directed back into the programs and services we provide to children with cancer.

SALE Prices until Dec. 10th

- ♥ 1-25 pins, \$2.00 each
- ♥ 26-50 pins, \$1.75 each
- ♥ 51-99 pins, \$1.50 each
- ♥ 100+ pins, \$1.25 each



Candlelighters' Hero Beads Now Available!

Children treated for cancer undergo an overwhelming number of medical procedures. Children can be faced with drug infusions, blood transfusions, surgery, bone marrow aspirates, lumbar punctures, finger pokes, and other invasive procedures. They often have to remain in the hospital for extended stays and sometimes travel to other cities for treatment.

Candlelighters' Hero Beads are designed to let children with cancer commemorate their personal cancer journey, while keeping a simplistic medical record. Every time that a child has a procedure—whether a chemotherapy infusion, radiation therapy, a bone marrow aspirate, a blood transfusion, or other procedures, their parent or a member from their medical team can provide them with a special bead to add to their 'bead necklace.' Each bead represents a specific treatment that the child received. For example, a red heart bead represents a blood transfusion. A glow-in-the-dark star wearing sunglasses symbolizes total body radiation. **The treatment legend and the associated beads can be seen on the following page and is also posted on Candlelighters' national website at: www.candlelighters.org**

Candlelighters' Beads provide a symbol of each child's unique cancer journey—a symbol that demonstrates the child's strength and accomplishments. Wearing the necklace can help their friends, school mates and extended family members to better understand what the child has been going through. Parents might also want to wear the Hero bead necklace to work as a means to visually share their child's cancer journey in a meaningful way with their colleagues.

Beads may be purchased individually by families or in bulk by hospitals and Candlelighters' Affiliated groups using our website store at www.candlelighters.org/store.

One Mom's Account of CCCF Hero Beads

Hello my friends,

I wanted to share with you that Alexander and I ordered his beads on the Candlelighters' website a few weeks ago and they arrived this week. When I came home from work, he told me that they had arrived in the mail and that he had already strung them together and made a necklace and a bracelet. They are really wonderful and understandably tell quite a story visually.

What I didn't know is that each child in his grade 7 class had to stand up in front of the class this week and share a story about something unique that they have experienced in their life. Alexander told me after this after it had already happened. Alexander chose to bring his beads and the Bead Legend that explains the meaning behind each of them to tell his story. He said that the kids were very interested and asked a lot of questions about his experience through Childhood Cancer. He also said that his teacher said to him that his story definitely qualified as "unique" and that she took him aside after class that day and told him that she was impressed with his maturity to share something so personal.

Alexander is on the verge of being a full-fledge teenager with the mood swings, the huge growth spurts (8 inches in height in the past year!), the deep bellowing voice, and the occasional rolling eyes when his Mom says something that is really dorky or embarrassing! (LOL). In spite of his fluctuation between being a child and becoming a teenager he felt confident and comfortable to bring these beads to school and to share this story with his friends and teacher. I was surprised but pleased that he felt it important to share something so personal, and it was received so well.

If you haven't checked out the website yet or purchased any beads, it is definitely worthwhile to check it out with your survivor.

Tami, mom to Alexander, 12 years of age (diagnosed with High Risk Leukemia, Long-term survivor!)



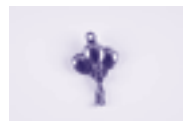






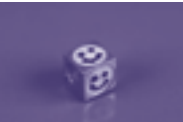






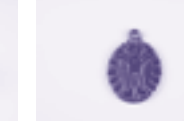
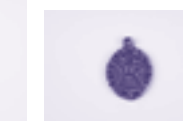

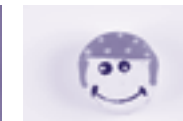

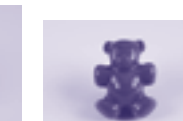

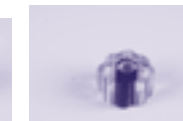


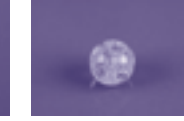


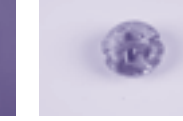

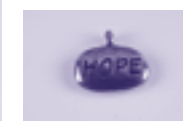
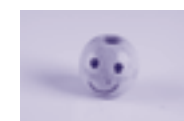

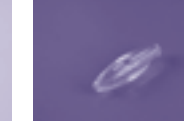
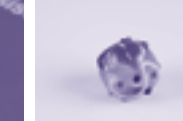

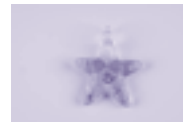



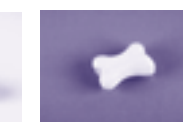
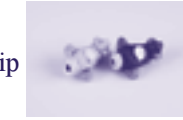
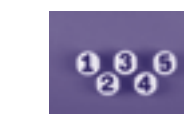
Join the thousands of childhood cancer families who are building awareness through the gold ribbon vehicle magnet. Take advantage of the webstore FALL SALE from now until the lighting of the National Awareness Tree on Dec. 10th and get your magnet for \$3.00 each!





BEAD LEGEND

Safety Warning: To avoid possible choking or strangulation, beads should only be worn with adult supervision. Children should NOT wear beads in bed, while playing, on climbing equipment, or while under sedation.

					
Air Lift	Biopsy Complete	Birthday on Treatment	Blood Transfusion	Bone Marrow Aspirate	Bone Marrow Transplant
					
Candlelighters' Kid	Cast	Central Line Surgically In	Central Line Surgically Out	Central Line/Port Access	Child's Name
					
Course Of Chemotherapy	CT Scan	Diagnosis	Echocardiogram	End of All Treatment, Boy	End of All Treatment, Girl
					
Finger Poke	Hair Loss	ICU/PICU	In-Hospital Admission	Intra-Muscular Injection (IM)	IV Infusion
					
Lumbar Puncture (LP)	Magnetic Resonance Imaging (MRI)	Nuclear Med. Scan	Oral Meds.	PET Scan	Platelet Transfusion
					
Radiation	Relapse	Remission, No Evidence Of Disease	Sedation	Shunt Insertion	Stem Cell Harvest
					
Surgery (General)	Total Body Radiation (TBI)	TPN	Travel Long Distance to Treatment	Tube Insertion Ng-Tube, G-Tube	X-Ray
			Years Off Treatment		
	Wish Trip		Years Off Treatment		



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Yes! I would like to help children with cancer and those who
care for them by making a tax-deductible gift of:

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Thank you for supporting Candlelighters

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lies of children with cancer, survivors of childhood cancer
and the professionals who care for them. IRS# 52-1071826

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This journal is written to provide informa-
tion about childhood cancer and should
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Email us at: staff@candlelighters.org
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Link to Candlelighters Childhood Cancer
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