



CANDLELIGHTERS

CHILDHOOD • CANCER • FOUNDATION™

The Quarterly Newsletter

SUMMER 2001

Childhood Cancer Awareness Days 2001 Activities to be held September 12-15, 2001

Included in the Next

Edition of

"The Quarterly"

- *Cognitive Late Effects: Part II*
- *Dr. Brian Druker reports on STI-571 (Gleevec)*

Now available on

Candlelighters website:

- *Current list of COG treatment centers*
- *Current list of Long Term Follow-Up Clinics*
- *Candlelighters' "Candlewear"*
- *Institution list for Enalapril Clinical Trial*

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September 2001 marks the second year that childhood cancer patients, survivors, families of children with cancer, researchers, and representatives will join together in the nation's capitol for Childhood Cancer Awareness Days. More than 22 organizations are involved to date, including Candlelighters Childhood Cancer Foundation, the National Childhood Cancer Foundation, the Children's Oncology Group, the American Cancer Society and others.

More than 12,000 young patients are diagnosed with cancer every year. Childhood cancer is the number one disease killer of children and adolescents in North America.

More children die of cancer than of any other disease, including asthma, diabetes, cystic fibrosis, congenital anomalies and AIDS, combined.

Childhood Cancer Awareness Days is a unique opportunity for those whose lives have been touched and forever changed by this deadly disease to unite, raise awareness and actively advocate for policies that would be of the greatest benefit to patients, caregivers, survivors and families.

Wednesday, September 12, 2001: Holiday Inn on the Hill

4-6 pm: *Legislative Workshop for childhood cancer advocates* – An informational



session on childhood cancer policy issues will prepare participants to advocate for various legislative issues and meet with Members of Congress and legislative staff.

Thursday, September 13, 2001: Childhood Cancer Awareness Day on Capitol Hill

8-9 am – *Kick-Off Breakfast:* Holiday Inn Capitol
10-11 am - *Childhood Cancer Rally:* Childhood cancer patients, families, caregivers and Members of Congress

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Even If It Worked, Cloning Wouldn't Bring Her Back

by Thomas H. Murray

Eleven days ago, as I awaited my turn to testify at a congressional hearing on human reproductive cloning, one of five scientists on the witness list took the microphone. Brigitte Boisselier, a

chemist working with couples who want to use cloning techniques to create babies, read aloud a letter from "a father, (Dada)." The writer, who had unexpectedly become a parent in his late thirties, describes his despair over

his 11-month-old son's death after heart surgery and 17 days of "misery and struggle." The room was quiet as Boisselier read the man's words: "I decided then and there that I would never give up on my child.

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Childhood Cancer Awareness Days *continued...*

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will gather on the West steps of the U.S. Capitol Building to show support for and draw attention to childhood cancer.

11:30 am-4 pm – **Childhood cancer advocates meet with Members of Congress:** Patients, survivors, parents, caregivers and others will meet with members of Congress and legislative staff to discuss timely policy issues related to childhood cancer. (Box lunches will be available throughout the day at Hospitality Room at Capitol Building (room number to be assigned).

Friday, September 14, 2001: Holiday Inn Capitol

8:30 am – 5:00 pm - **Parent Program:**
An opportunity to get to know other families of children with cancer as well as participate in information sessions.

8:30 am – 9:30 am – Breakfast

9:30 am – 11:30 am – Four Guest

CONTACT INFORMATION

The Candlelighters Childhood Cancer Foundation™

3910 Warner Street

Kensington, MD 20895

Ph: 301-962-3520 1-800-366-2223

Fax: 301-962-3521

Website: <http://www.candlelighters.org>

Email: info@candlelighters.org

Ruth Hoffman, *Executive Director
& Newsletter Editor*

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speakers provide insight to Current Treatment Trends with a focus on: 1/ Leukemia, 2/ Solid Tumors, 3/ Neuroblastoma and 4/ Brain Tumors. "Question the Expert" session to follow.

12:00 noon – 2:00 pm – Lunch and power-point tribute to "our kids".

2:00 pm - 3:30 pm – Concurrent sessions:
1/ Late effects of childhood cancer treatment

2/ Supportive Care – Paliation, Hospice and Grief.

3:30 pm – 5:00 pm – Social time for parents to mingle and work on a Childhood Cancer Awareness Project.

6:30 pm - Dinner

Saturday, September 15, 2001 Rays of Hope/Candlelight Vigil

All those touched by childhood cancer will have an opportunity to show their solidarity with others in the cancer community during this memorable event. Sponsored by the National Coalition for Cancer Survivorship, the Rays of Hope/Candlelight Vigil will be held at The Ellipse, located directly across from the White House. Preliminary events, including informational exhibits from various cancer organizations, are scheduled from 4-7 pm (approximate). The formal program, including the Candlelight Vigil, is scheduled for 7-8:30 pm.

*Schedule is subject to change.

A block of rooms have been reserved at the Holiday Inn on the Hill (415 New Jersey Avenue, NW) at a special rate of \$166 per night (this rate is available until August 11 or on a space-available basis). For reservations, call 1/800-638-1116 or 202/638-1615 and ask for reservation code "Childhood Cancer Days."

Updated information and registration forms can be found at: www.ChildhoodCancerAwareness.org

Registration Form

PLEASE COMPLETE A REGISTRATION FORM FOR EACH PARTICIPANT.

Name: _____

Adult
 Child (Age _____)

Address: _____

City: _____

State: _____ Zip: _____

Email: _____

WHICH EVENTS DO YOU PLAN TO ATTEND? (PLEASE CHECK ALL THAT APPLY)

Wednesday, September 12, 2001

- Legislative Workshop for advocates – 4-6 pm

Thursday, September 13, 2001
Childhood Cancer Awareness Day

- Kick-off breakfast - 8-9 am
 Childhood Cancer Gold Ribbon Rally on Capitol Hill – 10-11 am
 Visits with members of Congress and legislative staff* – 11:30 am-5 pm

Friday, September 14, 2001: Program for Parents – 10 am – 5 pm

- Morning session
 Afternoon session

Saturday, September 15, 2001

- Rays of Hope/Vigil

PLEASE SEND YOUR REGISTRATION FORM TO:

**CHILDHOOD CANCER AWARENESS DAYS 2001
3910 WARNER STREET
KENSINGTON MD 20895**

**FOR FURTHER INFO CALL:
800/458-6223 ext 193**

Cognitive Late effects in Leukemia Survivors

By Nancy Keene and Kevin Oeffinger MD

Changes in the way survivors of childhood cancer think, remember, and learn are called cognitive late effects. These problems with brain function are common in survivors of brain tumors and leukemia. To cover the topic in depth, we will write a two part series of articles. The first will be on the cognitive late effects in leukemia survivors. The second will talk about ways to address school and social issues that result from late effects to the brain. As with other late effects that we have addressed in previous articles, it is important to remember that each child is unique and many will not have the late effects discussed below.

Treatment and late effects in children treated in the 1970s

In the past, the most common site of recurrence of leukemia (return of the cancer after treatment) was the central nervous system (CNS), which includes the brain and the spinal cord. In the 1960's, more than half of children with ALL developed leukemia in the CNS. In most patients, CNS relapse was quickly a return of cancer cells in the blood stream. From this it was learned that in addition to treating the blood stream it was also important to treat the brain and spinal cord.

In the early 1970s both brain and spinal column radiation, referred to as craniospinal radiation, were used to prevent CNS relapse in children with leukemia. Doctors quickly learned that the spinal part of the radiation slowed or stopped growth of the spine, so only the brain was treated with radiation. This type of radiation, referred to as whole brain or cranial irradiation therapy, was given at a dose of 24 Gy. Gy is a

measure of radiation. 24 Gy is the same dose as 2400 cGy.

This use of whole brain radiation revolutionized the treatment of childhood leukemia, as the rate of return of the cancer in the CNS went from 50% to less than 10%. However, it was soon recognized that this marked increase in cure rates often came at a cost. Many survivors developed cognitive dysfunction (cognitive = thinking process; dysfunction = abnormal function). This occurred because tissues of the brain are very sensitive to radiation. The dose and location of radiation, age, sex, and individual vulnerability all play a role in how much the radiation affects brain function. Those at highest risk to develop problems are children under the age of two. Children under the age of five are at high risk, with girls showing a greater sensitivity to radiation than boys. However, any child whose brain is irradiated may develop long-term changes in brain function.

Damage from radiation to the young brain typically does not appear until two to five years after the radiation. In the early 1980s, a number of studies on children who were treated with brain radiation in the 1970s showed that 24 Gy could significantly affect the thinking process of survivors. The IQ of the average survivor decreased by about 10 points, with the verbal scores being most affected. Although more than half of survivors had mild to moderate learning problems, there was a lot of variation among survivors. Some patients experienced 20 to 30 point losses while many others had no changes at all. Problems were

noted in measures of visual-spatial abilities, attention, concentration, nonverbal memory, and mathematics.

A study by the Children's Cancer Group looked at the impact of 24 Gy brain radiation on school performance of survivors in comparison with their brothers and sisters. Survivors were 4 times as likely to enter special education and 5 times as likely to enter learning

disabled programs as the siblings. On the bright side, survivors were just as likely to enter gifted and talented programs as their brothers or sisters. In general, survivors were as likely to finish high

school. There were no differences between males and females in educational achievements.

Treatment in the 1980s and 1990s

Because of the problems that developed after 24 Gy, other treatment plans that could prevent return of the cancer to the central nervous system were studied. The three main treatment options used were: (1) lower dose of radiation (18 Gy) with intrathecal methotrexate (chemo medication given in the fluid that surrounds the spinal cord and brain), (2) more intense chemotherapy with high dose methotrexate to the whole body (systemic) and in the spinal fluid, or (3) use of three medications, including methotrexate, given in the spinal fluid (called triple intrathecal). The last of these three options, using the three medications in the spinal fluid, was found to sometimes cause seizures and other similar problems during treatment, and so most treatment plans now

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Changes in the way survivors of childhood cancer think, remember, and learn are called cognitive late effects.

Cognitive Late effects in Leukemia Survivors *continued...*

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use one of the first two approaches.

Because of the location of the leukemia or the genetic makeup of the cancer cells, some leukemia patients have less of a chance to be cured of their cancer. There has been a great deal of research to find out who these patients are soon after diagnosis so that they can receive more intense treatments (brain radiation and chemotherapy) in hopes of curing the cancer and preventing it from coming back. Needless to say, these intense treatments can often cure the cancer but also may also cause problems in survivors. Conversely, better identification of those at high risk, allows all of the others to receive milder treatments with less likelihood of long-term side effects.

Though it will take several years and more studies to better understand the late effects of these newer treatment plans, the damage from these treatments will be much less than some survivors experienced from 24 Gy brain radiation. Small studies following survivors who were treated with 18 Gy brain radiation have shown that fewer survivors have problems with thinking and learning skills and those who do have problems usually have milder ones than survivors who were treated with 24 Gy brain radiation. Even more encouraging, recent studies suggest that leukemia survivors treated with chemotherapy alone generally have fewer cognitive late effects than those who received radiation.

Identifying the late effects

It is important for parents and educators to remain vigilant for potential learning problems so that if they are found, help at school can be started. The signs of possible learning disabilities are problems with:

- Handwriting

- Spelling
- Reading or reading comprehension.
- Understanding math concepts, remembering math facts, comprehending math symbols, sequencing, and working with columns and graphs.
- Difficulty in using calculators or computers.
- Auditory or visual language processing. These children have trouble with vocabulary, blending sounds, and syntax.
- Attention deficits. Some children become either inattentive or hyperactive or both. These behaviors are indicative of neurologically-based deficits in attention, which can cause children to be more impulsive and distractible than their peers.

Damage from radiation to the young brain typically does not appear until two to five years after the radiation.

- Short-term memory and information retrieval.
- Planning and organizational skills.
- Social maturity and social skills.

You should also suspect learning difficulties if:

- Your child was an A student prior to cancer, and she is working just as hard and getting Cs.
- Your child takes three hours to do homework that used to take one hour.
- Your child reads a story and then has trouble explaining the plot.
- Your child frequently comes home frustrated from school, saying he just doesn't understand things as well as the other kids.

- Your child's teacher complains that she "just doesn't pay attention" or "just needs to work harder."

If any of the above situations are occurring, take action to begin the evaluation process before your child's self-esteem plummets. It is sometimes hard to take this first step because children affected by radiation and/or chemotherapy can reason well and think clearly and may be above average academically in several areas. They may fall behind their classmates, however, on tasks that require fast processing skills, short-term memory, sequential operations, and organizational ability (especially visual). Once identified, these differences can be addressed by strategies such as resource services in memory enhancement, eliminating timed tests, improving organizational skills, and providing extra help in mathematics, spelling, reading, and organization.

Whatever your child's treatment, awareness of the potential for learning problems will help you identify any late effects early. The next article will focus on testing and interventions to address cognitive changes in survivors of childhood cancer. Many children with learning problems do extremely well in school with appropriate accommodations.

Dr. Kevin Oeffinger MD directs a multi disciplinary program for young adult survivors of childhood cancer at UT Southwestern at Dallas TX and is partially supported as a Robert Wood Johnson Foundation Generalist Physician Faculty Scholar. He enjoys backpacking, running and hiking with his wife Patty, 16-year-old son Daniel and 13-year-old daughter Ashley.

Nancy Keene is the author of Childhood Leukemia, Childhood Cancer (with co-author Honna Janes-Hodder), Your Child in the Hospital, Working with Your Doctor and Childhood Cancer Survivors (co-authored with Wendy Hobbie RN and Kathy Rucione). She is Chair of the Patient Advocacy Committee of COG (Children's Oncology Group) and mother of 12-year-old Kathryn who is a survivor of high risk ALL and 10-year-old daughter Alison.

Even If It Worked, Cloning Wouldn't Bring Her Back...*continued...*

(Continued from page 1)

I would never stop until I could give his DNA -- his genetic make-up -- a chance."

I listened to the letter writer's refusal to accept the finality of death, to his wish to allow his son another opportunity at life through cloning, and I was struck by the futility and danger of such thinking. I had been asked to testify as someone who has been writing and teaching about ethical issues in medicine and science for more than 20 years; but I am also a grieving parent. My 20-year-old daughter's murder, just five months ago, has agonizingly reinforced what I have for years argued as an ethicist: Cloning can neither change the fact of death nor deflect the pain of grief.

Only four years have passed since the birth of the first cloned mammal -- Dolly the sheep -- was announced and the possibility of human cloning became real. Once a staple of sci-

ence fiction, cloning was now the stuff of scientific research. A presidential commission, of which I am a member, began to deliberate the ethics of human cloning; scientists disavowed any interest in trying to clone people; and Congress held hearings but passed no laws. A moratorium took hold, stable except for the occasional eruption of self-proclaimed would-be cloners such as Chicago-based physicist Richard Seed and a group led by a man named Rael who claims that we are all clones of alien ancestors. Recently, Boisselier, Rael's chief scientist, and Panos Zavos, an infertility specialist in Kentucky, won overnight attention when they proclaimed that they would indeed create a human clone in the near future. The prospect that renegade scientists might try to clone humans re-ignited the concern of lawmakers, which led to the recent hearings before the House Energy and Commerce subcommittee on

oversight and investigations.

Cloning advocates have had a difficult time coming up with persuasive ethical arguments. Indulging narcissism -- so that someone can create many Mini-Me's -- fails to generate much support for their cause. Others make the case that adults should have the right to use any means possible to have the child they want. Their liberty trumps everything else; the child's welfare barely registers, except to avoid a life that would be worse than never being born, a standard akin to dividing by zero -- no meaningful answer is possible. The strategy that has been the most effective has been to play the sympathy card -- and who evokes more sympathy than someone who has lost a child? Sadly, I'm in a position to correct some of these misunderstandings. I'm not suggesting that my situation is the same as that of the letter's author. Not better. Not

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Baboo's Patch



Baboo's Patch is a medical tube retainer apparatus, designed to hold a central venous line catheter. This easy to apply, iron-on patch can be added to the inside of any tee-shirt that your child owns. The washable patch assists with the child's ability to move around freely, by supporting external central venous line tubing. Tubing is no longer taped to sensitive skin or left dangling for possible dislodgement. "Baboo's Patch was created by Valerie Buchesneau for her six year old son Anthony, nicknamed: Baboo while he was undergoing a bone marrow transplant for the treatment of his cancer (neuroblastoma IV). In honor of Anthony's brave spirit, Valerie has continued to make Baboo's Patch available to other cancer children.

Costs for each patch:

- Regular Patch: \$12.50
- Boy Patch: \$14.50
- Girl Patch: \$14.50
- Sports Patch: \$16.50
- Butterflies Patch: \$16.50

To order "Baboo's Patch", please visit www.baboospatch.com (Email: baboospatch@aol.com) or send your order with accompanying check or money order directly to:

Valerie Duchesneau
7 East / 61st. Street
Savannah , GA 31405.

Free shipping and handling.
 (GA residents, please add 6% sales tax).

Even If It Worked, Cloning Wouldn't Bring Her Back ...continued...

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worse. Simply different. His son was with him for less than a year, our daughter for 20; his son died of disease in a hospital; Emily, daughter to Cynthia and me, sister to Kate and Matt, Nicky and Pete, was reported missing from her college campus in early November. Her body was found more than five weeks later. She had been abducted and shot.

As I write those words, I still want to believe they are about someone else a story on the 11 o'clock news. Cynthia and I often ask each other, how can this be our life? But it is our life. And Emily, as a physical, exuberant, loving presence, is not in the same way a part of it anymore. Death changes things and, I suspect, the death of a child causes more wrenching grief than any other death. So I am told; so my experience confirms.

I want to speak, then, to the author of that letter, father to father, grieving parent to grieving parent; and to anyone clinging to unfounded hope that cloning can somehow repair the arbitrariness of disease, unhappiness and death. I have nothing to sell you, I don't want your money, and I certainly don't want to be cruel. But there are hard truths here that some people, whether through ignorance or self-interest, are obscuring.

The first truth is that cloning does not result in healthy, normal offspring. The two scientific experts on animal cloning who shared the panel with Boisselier reported the results of the cattle, mice and other mammals cloned thus far: They have suffered staggering rates of abnormalities and death; some of the females bearing them have been injured and some have died. Rudolf Jaenisch, an expert on mouse cloning at MIT's

Whitehead Institute for Biomedical Research, told the subcommittee that he did not believe there was a single healthy cloned mammal in existence -- not even Dolly, the sheep that started it all, who is abnormally obese.

The first truth is that cloning does not result in healthy, normal offspring.

The second truth: Even if cloning produced a healthy embryo, the result would not be the same person as the one whose genetic material was used.

Scientists do not know why cloning fails so miserably. One plausible explanation begins with what we already know -- that as the cells of an embryo divide and begin to transform into the many varieties of tissue that make up our bodies, most of the genes in each cell are shut down, leaving active only those that the cell needs to perform its specific role. A pancreatic islet cell, for example, needs working versions of the genes that recognize when a person needs the hormone insulin, then cobble it together and shunt it into the bloodstream. All of that individual's other genetic information is in that islet cell, but most of it is chemically locked, like an illegally parked car immobilized by a tire boot.

To make a healthy clone, scientists need to unlock every last one of those tire boots in the cell that is to be cloned. It is not enough to have the genes for islet cells; every gene will be needed sometime, somewhere. Unless and until scientists puzzle out how to restore all the genes to their original state, we will continue to see dead, dying and deformed clones.

You do not need to be a professional bioethicist, then, to see that trying to make a child by cloning, at this stage in the technology, would be a gross violation of international standards protecting people from overreaching scientists, a blatant example of immoral human experimentation.

Some scientists claim they can avoid these problems. Zavos, who spoke at the hearing, has promised to screen embryos and implant only healthy ones. But Zavos failed to give a single plausible reason to believe that he can distinguish healthy from unhealthy cloned embryos.

Now for the second truth: Even if cloning produced a healthy embryo, the result would not be the same person as the one whose genetic material was used. Each of us is a complex amalgam of luck, experience and heredity. Where in the womb an embryo burrows, what its mother eats or drinks, what stresses she endures, her age -- all these factors shape the developing fetus. The genes themselves conduct an intricately choreographed dance, turning on and off, instructing other genes to do the same in response to their interior rhythms and to the pulses of the world outside. How we become who we are remains a mystery. About the only thing we can be certain of is that we are much more than the sum of our genes. As I said in my testimony, perhaps the best way to extinguish the enthusiasm for human cloning would be to clone Michael Jordan. Michael II might well have no interest in playing basketball but instead long to become an accountant. What makes Michael I great is not merely his physical gifts, but his competitive fire, his determination, his fierce will to win.

Yet another hard truth: Creating a child to stand in for another -- dead -- child is unfair. No child should have to bear the oppressive expectation that he or she will live out the life denied to his or her idealized genetic avatar.

Parents may joke about their specific plans for their children; I suspect their children find such plans less amusing. Of course, we should have expectations for our children: that

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Childhood Cancer Patient Advocate Dies

Tribute to Dan Fiduccia

As Dan Fiduccia's body slowly wasted away from the blasts of radiation that helped him survive childhood cancer, his heart and intellect seemed to grow and deepen. By the time he was 44, the toddler who had defied the odds by beating cancer in the 1950s had grown into a ferocious and successful advocate for young cancer patients and childhood survivors like himself. Using his training as a paralegal and as a disability rights advocate, Fiduccia helped adult survivors, young cancer patients and their families fight discrimination in insurance, Social Security, education and the workplace.

He and his wife, Barbara, waged -- and ultimately won -- a high-profile battle against Social Security provisions that penalized them financially if they were to be married. Then in late March, Fiduccia was diagnosed with cancer in his abdomen and he learned that it had spread. He was hospitalized with pneumonia and he died a week later surrounded by family and friends. He is the oldest known survivor of Wilms tumor.

"He knew what needed to be done in the world and he did it until he couldn't do it anymore," his wife Barbara said.

Over the years, Fiduccia had become increasingly disabled as a result of the childhood cancer treatment, which one friend compared to the radiation unleashed by the bomb the United States dropped on Hiroshima. Although he masked it well, in recent years he was in near constant pain. In the last year, he had begun to slow down. He started preparing for the end by reading books and watching documentaries that dealt with how men, particularly soldiers, faced death.

Friends describe Fiduccia as having a brilliant mind and a lifelong love of learning, which he indulged as a young man at Stanford University. But as much as anything, his hallmark was a passionate tenacity that at times bordered on obsession. Quite simply, he refused to give up. "I won't submit," he would say.

Grace Powers Monaco, whose Medical Care Ombudsman Program employed Fiduccia as an advocate, met him more than a decade ago, when he was referred to her for help with an insurance question. "I realized what a brilliant guy he was, so after we resolved his problem, I wouldn't let him go," she said. Together, she and Fiduccia and another colleague, Gib Smith, have written extensively on managed care, insurance problems and other matters of interest to patients and health-care providers. Her friend, she said, had a sharp wit and black sense of humor, which was fed by his keen intelligence. "His specialty was finding solutions to insoluble problems," she said. "He cannot be replaced."

Fiduccia and his then-fiancee, Barbara Waxman, were featured in the Mercury News' Sunday magazine in a 1995 story headlined "Marry or Cheat?" They were fighting a system that severely penalized disabled people such as Mrs. Fiduccia, who has spinal muscular atrophy (SMA), for marrying. If her income increased because of marriage, she would lose medical and home-care benefits that were critical to her survival and quality of life. After an initial, crushing defeat in Congress, the couple eventually prevailed. They were married on July 28, 1996, and set up housekeeping in Cupertino. It was Fiduccia's sweetest victory. Their love affair began after they met in 1992 at a training session for

BY BECKY BARTINDALE

disability advocates. By then, Waxman had given up on marriage. She had thrown herself into her work as an advocate for disabled women's rights. "As soon as I saw him, even without talking to him, I felt I knew him," she said. "There was a moment of connection."

Childhood radiation treatments had weakened Fiduccia's immune system and stunted his bone growth. His spine became increasingly curved and stiff. It became difficult to sit and walk. Fiduccia ran various entrepreneurial ventures out of his home, but most of his work was as a disabilities rights consultant. His bookcase is lined with photographs of the children for whom he fought. "Many of them had died of brain tumors or other cancers, but he kept the pictures of them," Mrs. Fiduccia said. "He suffered a lot when they died. He had a good healthy anger at the system and he used it to win many cases both for many people and himself, and for us and our marriage." Fiduccia had the heart of a warrior, not social worker. "He would push parents to help get things done," his wife said. "He did the same thing with me. He helped me grow up a lot and face a lot of things about myself. He helped me blossom as a human being." Said his friend Ed Kohn: "The most amazing thing is that he lived as long as he did and he was as productive as he was able to be. He helped so many people despite his problems, which grew increasingly complex as he got older. He would never say, 'No, I can't help you.'"

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Candlelighters will be forever grateful to Dan for the free legal counsel that he provided to so many families of children with cancer. Soar in Peace.

Postage Stamp Campaign for Childhood Cancer Awareness

Please help us honor our children by participating in a writing campaign to attempt to get a stamp approved for childhood cancer. Currently, there are stamps for breast and prostate cancer, diabetes, organ donation and hospice. Each year, the citizen's stamp advisory committee reviews stamp subjects that are submitted by the public. They have thousands that are suggested. They will only consider "events and themes of widespread national appeal and significance". It is quite possible that they do not know the widespread national significance of childhood cancer. We are asking each of you - family members of children with cancer, childhood cancer patients, survivors, friends

and care-givers to help us tell them that childhood cancer is the number one disease killer of children in our country, and that the number of kids being diagnosed with cancer is increasing. Let us tell them that treatment can take up to two or three years. Let us tell them that one in 900 young adults is a survivor of childhood cancer. Let us tell them that childhood cancer is significant! Please send a letter in support of a childhood cancer stamp to:

**Citizens Stamp Advisory Committee
c/o Stamp Development
U.S. Postal Service
475 L'Enfant Plaza, SW,
Room 5670
Washington, D.C. 20260-2437**

**Template Letter
(available on our website at:
www.candlelighters.org)**

Dear Advisory Committee,
We respectfully submit for your consideration and approval, the proposal of a "Childhood Cancer Awareness" postage stamp. As parents whose lives have been forever changed by this disease, we hope that this stamp could be given designation as a symbol for childhood cancer awareness.

By age 20, one child or teen in 330 is diagnosed with cancer. Each year, 12,400 new cases of childhood cancer are diagnosed in the United States. Each school day, 46 children or two entire classrooms of children are diagnosed with cancer. Each day researchers, scientists and physicians come a little closer to finding successful treatments for many childhood cancers, yet approximately 2300 children and adolescents die each year. More children die of cancer than of any other disease, including asthma, diabetes, cystic fibrosis, congenital anomalies and AIDS, combined.

Treatment for childhood cancer is intense, often lasting several years of precious childhood. While more and more of our children are surviving their cancers, they emerge from their hard-fought battles to be then faced with the late effects of their treatment. These effects can range from mild learning difficulties to severe multiple disabilities, both physical and cognitive. Our children often pay a high price for their survival.

Motivated by the extraordinary success of the breast cancer stamp, the existence of a "Childhood Cancer Awareness" stamp would serve to promote the awareness of this disease that is plaguing our children.

No parent ever wants to hear the words, "Your child has cancer." Yet one in 330 families in the United States are handed this fate. Mine included. Please help to promote the necessary advocacy for awareness and research that a "Childhood Cancer Stamp" would provide. Thank you very much for your consideration.

Participants Needed For PROCRIT Study PR99-11-034: Pediatric Solid Tumor/Hodgkin's Disease Study PR99-11-044: Pediatric ALL/NHL Study

Two multi-center Phase IIIB trials are underway to determine the effects of PROCRIT® (Epoetin alfa) on anemia and quality of life in children with cancer who are undergoing myelosuppressive chemotherapy. One study will include children who are diagnosed with Malignant Solid Tumors or Hodgkin's Disease; the other study will include children diagnosed with Acute Lymphocytic Leukemia (ALL) or Non-Hodgkin's Lymphoma (NHL). PROCRIT is a drug that treats anemia and works by increasing the production of red blood cells. Eligible patients will be randomized to receive either PROCRIT or Placebo once weekly. Changes in the participants' quality of life, hemoglobin levels, and transfusion requirements will be used to evaluate the drug's effectiveness.

As with all clinical trials, individuals must meet specific criteria to participate in this study. The eligibility criteria include newly diagnosed patients who are 5 through 18 years of age and anemic for their age and gender. The first cycle of chemotherapy should be scheduled to be given within one week, or may have been given within the previous month. Scheduled chemotherapy should continue for a minimum of 12 weeks after study enrollment. Patients are required to have an indwelling central venous access device or peripheral intravenous catheter in place for chemotherapy administration. Patients who are diagnosed with any myeloid malignancy or central nervous system (CNS) disease/tumor, or scheduled to receive CNS irradiation are not eligible for participation. Patients with certain other medical conditions, such as an inherited form of anemia, uncontrolled hypertension, or seizure disorder, are also not eligible.

Several Pediatric Oncologists throughout the United States are participating in this study. If interested, talk with your child's treating oncologist. For more information and to find a clinical trial site closest to you call (215) 591-6645.

Even If It Worked, Cloning Wouldn't Bring Her Back...continued..

(continued from page 6)

they be considerate, honest, diligent, fair and more. But we cannot dictate their temperament, talents or interests. Cloning a child to be a reincarnation of someone else is a grotesque, fun-house mirror distortion of parental expectations.

Which brings me to the final hard truth: There is no real escape from grief.

Cynthia and I have fantasized about time running backward so that we could undo Emily's murder. We would give our limbs, our organs, our lives to bring her back, to give her the opportunity to live out her dream of becoming an Episcopal priest, of retiring as a mesmerizing old woman sitting on her porch on Cape Cod, surrounded by her grandchildren and poodles.

But trying to recreate Emily from her DNA would be chasing an illusion. Massive waves of sorrow knock us down, breathless; we must learn to live with them. When our strength returns we stagger to our feet, summon whatever will we can, and do what needs to be done. Most of all we try to hold each other up. We can no more wish our grief away than King Canute could stem the ocean's tide.

So I find myself wanting to say to the letter writer, and to the scientists who offer him and other sorrowing families false hope: There are no technological fixes for grief; cloning your dear dead son will not repair the jagged hole ripped out of the tapestry of your life. Your letter fills me with sadness for you and your wife, not just for the loss of your child but also for the fruitless quest to quench your grief in a genetic replica of the son you lost. It would be fruitless even -- especially -- if you succeeded in creating a healthy biological duplicate. But there is little chance of that.

Emily lived until a few months shy of her 21st birthday. In those years our lives became interwoven in ways so intricate that I struggle for words to describe how Cynthia and I now feel. We were fortunate to have her with us long enough to see her become her own person, to love her wholeheartedly and to know beyond question that she loved us. Her loss changes us forever. Life flows in one direction; science cannot reverse the stream or reincarnate the dead.

The Emily we knew and loved would want us to continue to do what matters in our lives, to love each other, to do good work, to find meaning. Not to forget her, ever. We are incapable of that. Why would we want to? She was a luminous presence in our family, an extraordinary friend, a promising young philosopher. And we honor her by keeping her memory vibrant, not by trying to manufacture a genetic facsimile. And that thought makes me address the letter's author once more: I have to think that your son, were he able to tell you, would wish for you the same.

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Status of Cloning in the 107th Congress:

House of Representatives

House Leadership has instructed the House Energy and Commerce Committee and the House Judiciary Committee to hold hearings on reproductive and therapeutic cloning, with further consideration of legislation to be debated on the House floor. At this time, Representative Dave Weldon (R-FL) has introduced the Human Cloning Prohibition Act of 2001, H.R. 1644. The bill criminalizes the technique of cloning human beings known as somatic cell nuclear transfer. The legislation bans both reproductive

cloning, creating live-born human children, as well as therapeutic cloning, the creation of embryos for research or as sources of cells and tissues for possible therapeutic treatments. The bill currently has 88 co-sponsors.

The bill acknowledges that scientifically and medically useful practices of cloning of DNA fragments, known as molecular cloning, the duplication of somatic cells (or stem cells) in tissue culture, known as cell cloning, and whole-organism or embryo cloning of nonhuman animals are appropriate uses of medical technology. However, the bill prohibits human cloning, defined as somatic cell nuclear transfer to "produce a living organism (at any stage of development) with a human or predominantly human genetic constitution."

At this time, several pro-biomedical research Members of Congress are planning to introduce an alternative bill, prohibiting any attempt to clone a human being using somatic cell nuclear transfer. However, the legislation only addresses reproductive cloning, and prohibits the implantation or attempt to implant the product of somatic cell nuclear transfer into a woman's uterus. The legislation is expected to mirror Senator Dianne Feinstein's bill from the 105th Congress, Prohibition on Cloning of Human Beings Act of 1998. Currently, a draft bill is not available.

Senate

Senator Sam Brownback (R-KS) introduced the Human Cloning Prohibition Act of 2001, S. 790, in the Senate, identical to the Weldon bill. With the recent change in leadership in the Senate, the focus on cloning is uncertain. Senator Ted Kennedy (D-MA) has assured therapeutic cloning advocates that he will introduce an alternative bill should a debate on cloning ignite in the Senate. Senator Kennedy is expected to reintroduce the 1998 Feinstein bill, Prohibition on Cloning of Human Beings.

Opening The Door To Change

Two days before my fifteen-year-old son died he thumbed through a stack of cancer support-related newsletters.

"So why do you suppose when a person dies, they say he's lost the battle?" my son questioned. His face was pinched with confusion. Before I could say anything to Jay, he said next, "Don't worry Mom, I know dying is not losing." And with the zeal of a kid determined to restore order to the universe he announced, "Heaven is filled with winners." Following my son's death I received a heaping stack of cards from earnest friends; sweet messages almost restored my small courage, yet nearly all contained the lines, "We're so sorry Jay lost the fight."

Everyday I witness numerous random acts for which I call winning: the child who reassures a new friend that, "her hair will too grow back." The teenager who drags his IV pole from his bed to sit outside with friends. The young mother who allows a Hospice nurse to help her wash her hair and take a bath. Everyday ordinary people are called upon to do extraordinary things; like finding happiness and a good life in the midst of a cancer diagnosis.

In the final days of his life, my son helped me understand that we should not think of those facing a life threatening illness as "fighting it" or "beating it back."

By Terra Trevor

We don't want to struggle or battle with cancer. Rather it's about choosing life, living as well as you are able and loving more than you ever thought possible.

Terra Trevor is a volunteer veteran parent for NBTF/We Can Pediatric Brain Tumor Network, and the Program Director for American Indian Health & Services Red Ribbon Bridge HIV/AIDS in Santa Barbara, California.

Her son Jay was a 7.5 year survivor of an Anaplastic Ependymoma brain tumor. The tumor recurred in 1999 in the brain stem and he died in 1999.

New Resources:

Angel in Blue, The Story of Ashley Martin

by 5th grade students at Smith Road Elementary School



Angel in Blue, is a book written by 5th grade students at Smith Road Elementary School, Temperance Michigan, as a loving tribute to their classmate Ashley, who passed away from cancer in December of 1999. The student's thoughtful overview is not so much about loss and grief, but rather an upbeat collection of situations and quotes that help the reader get to know this incredible girl. They share her hopes, wisdom, and challenges in a way that is both realistic and touching. Accompanied by the illustrations of a very gifted young artist, this book will have you laughing, crying, and wanting to learn a lot more about this very special angel. **Angel in Blue** won first place in the Scholastic *Kids are Authors* contest in 2000, and was published with an initial print-run of 30,000 copies, which immediately sold out. Scholastic has printed 90,000 copies as of May 2001, which are available at local Scholastic bookfairs, or by calling Smith Road School at 734-850-6400. The book, which costs \$4.99 is also available through Barnes and Noble. The ISBN is 0-439-26065-5



Email:
captainchemo@royalmarsden.org



Captain Chemo is a free, interactive online game. "A comic strip superhero - devised by a teenage cancer patient and brought to life in a computer game and website by The Royal Marsden Hospital - is about to star in a brand new adventure to help other young sufferers fight the disease.

In the latest chapter of the Adventures of Captain Chemo - to be launched in the Royal Marsden's 150th anniversary year - the cancer superhero returns to educate and inspire young cancer patients all over the world. He is joined by Chemo Cadets Prednisolone, Etoposide and Vincristine - each named after a different chemotherapy drug - to combat a new enemy 'Bacteria' or what Captain Chemo technically calls a 'bug!' To learn more about Captain Chemo, visit <http://www.royalmarsden.org.uk/captchemo/>

In-Memoriam Donations

In-memoriam donations allow Candlelighters to continue providing services to families of children with cancer. We thank all those who have made a contribution in memory of a loved one.

I See You In My Everyday

*I see you in the peace of night
I see you in the bright sunlight
You're in the breeze that gently blows
You are the calm of fallen snow
Magnificent are wings that fly
I see you in the eagle's eye
You're in the turquoise of the sea
I can even see you in parts of me
I smell you in the lilac trees
I hear you in the bumblebees
You are the colors of the fall
You are the mountains soaring tall
I feel you in the summer storm
And in the springtime nice and warm
You are the blossoms on the branch
You're in the firefly's evening dance
I remember you in all good things
In the wondrous treasures nature
brings
Your memory will forever be
The greatest gift you gave to me.*

By Lauren Waters

Aaron Peterson
Alison Johnson
Alyce Gersonde
Amy Buchan
Andy Andrews
Ashley Adinolfi
Bradford Lambert
Brian Todd
Brianna Perry
Bryan M'Gehee McMahan
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Candlelighters encourages supporters to visit our on-line store for a variety of articles, including t-shirts, sweat shirts, denim shirts, beach bags, as well as our Childhood Cancer Awareness CD, You Can Fly.



Payments may be made using Visa or Mastercard.

Order on the web at:

www.candlelighters.org.

*Click on store on the directory.

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General donations can also be made through our website. Your donation assists us to provide on-going services to families of children with cancer without charge. Thank you for your continued support.

We welcome letters to the editor: poetry, photos, short stories, and other material from readers. Articles are selected for space and may be edited. Please write your name and address on the back of any photo that you would like returned to you.

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**...Because Kids Can't Fight
Cancer Alone!**

We're on the Web
www.candlelighters.org

Link to Candlelighters Childhood Cancer Foundation Website at: <http://www.candlelighters.org> to find the latest copy of our quarterly newsletter, our mission statement, publications list, local group information and membership sign up form.

**Email us at:
info@candlelighters.org**

We encourage you to continue to visit the site regularly as new links to affiliated organizations and other health-related websites are added regularly.

*"It is better to light
one candle than to
curse the darkness"*