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

Candlelighters™
Childhood Cancer Foundation

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The Quarterly Journal of the National Office

Family Medical Leave Act and Childhood Cancer

by Ruth I. Hoffman

The burden of responsibility for health care in the USA often fluctuates between the "individual" and "society." While there are mechanisms such as Medicare for the elderly, and Medicaid for the poor, the bulk of responsibility for care rests with the individual and the arrangements they can make for themselves and their family. In the case of the young family needing to provide care for their child who is diagnosed with cancer, this arrangement carries with it a dual responsibility of needing to provide both health insurance coverage for their child, as well as assist with providing essential clinical care to their cancer child. Parents work closely with the health care team, to provide care with responsibilities variably including: drug administration (oral toxic chemotherapy, antibiotics,anti-fungals, antiemetics, pain medications), intramuscular injections, saline flushing of central venous line(s) and g-tubes, monitoring of excess bruising and energy level necessitating the need for transfusion of blood products, provision of germ free environment, ventilator care, administration of Total Parenteral Nutrition (TPN), physiotherapy, occupational therapy, speech therapy, and home schooling (for school aged children). Parents also provide psychosocial care as their children endure drug induced hair loss, nausea and vomiting, chronic fatigue, weight loss or gain, diarrhea or constipation, emotional mood swings, loss of coordination, and inability to concentrate. The involvement of parent(s) in their child's clinical care is both in the inpatient and ambulatory care setting, and has become the "Standard of Care" for pediatric oncology.

The parent's ability to provide such essential care however, is severely compromised by the current Federal US employment policy—Family Medical Leave Act (FMLA) of 1993, where 12 weeks of un-paid family leave is allowed to provide care for a child for those individuals who are employed in large companies with over 50 employees. Currently, there is no existing federal leave policy allowing for paid family leave or for unpaid family leave for individuals who work for companies with less than 50 employees. Treatment for childhood cancer is often intensive and lengthy. It is not uncommon for one

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Join the Vehicle Magnet Craze and Build Childhood Cancer Awareness!

Wondering how you can increase awareness of childhood cancer? How about adding a childhood cancer awareness magnet to the back of your vehicle? Three different "Awareness magnets" are now available on Candlelighters' website by clicking on the store link. For **$5.00** you can help build awareness of childhood cancer simply while driving your car or van. All sale proceeds are directed back to supporting Candlelighters' programs.

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Oliver's Story: For "Sibs" of Kids with Cancer

Candlelighters Releases Another Book!

Siblings of children diagnosed with cancer have special needs both at school and at home. As extensive time is spent by the parents caring for their ill brother or sister, siblings of children with cancer may wonder what their role is during this time of family crisis. To assist siblings of children with cancer during this difficult time, Candlelighters' National office has published another valuable resource. Oliver's Story: For "Sibs" of Kids with Cancer is a 40 page illustrated book targeted for the 4- to 10-year old sibling. Illustrated by Mike Dodd and written through the eyes of his six-year-old son Oliver, this resource focuses on the many questions that siblings have when their brother or sister is diagnosed with cancer, and offers constructive ways on how they can provide support.

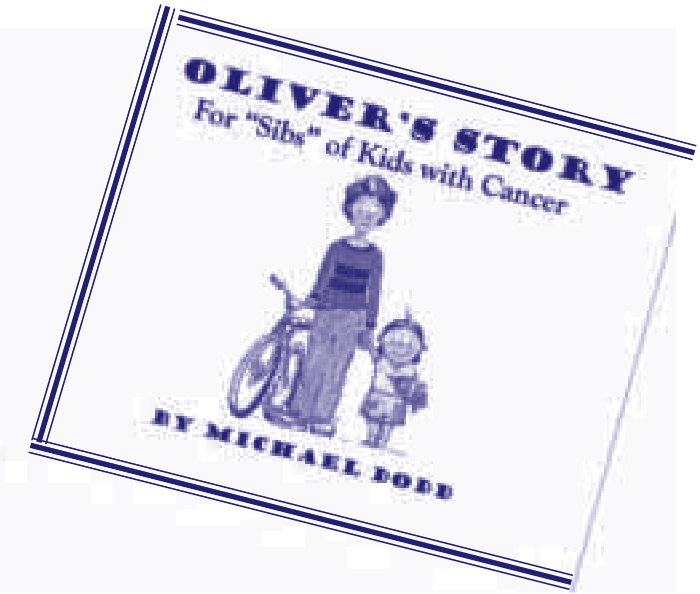
As discussed in Chapter 19 of Candlelighters' resource entitled ***Educating the Child with Cancer: A Guide for Parents and Teachers***, parents and other adults often assume that the other children in the family may not be aware of their sibling's illness or are not impacted by it. They may even be reluctant to share information about the illness in an effort to "protect" their other children. But the reality is that even very young children will be aware that something serious is happening and will notice that their family has changed. They may experience some of the following emotions.

- **Worries and fears**: Siblings of children with cancer often worry about their brother or sister's health. They may be afraid that the ill child will die. They may also worry about their own health, thinking they too might "catch" cancer. In addition, children worry about how their parents are coping or whether their family will ever get back to normal.

- **Guilt:** Brothers and sisters may wonder if something they thought, said, or did caused the cancer.

- **Jealousy**: Because the ill child is receiving extra attention, special privileges, or gifts, brothers and sisters might feel left out and jealous.

- **Loneliness:** Brothers and sisters miss their parents and ill sibling when they are away at the hospital or at the clinic. They may miss their friends too if they need to go away to stay with another relative or if visits are restricted because of low blood counts.



- **Anger and resentment**: Brothers and sisters may feel angry or resentful because their routines are disrupted, and they miss out on fun events or activities. In addition, they don't get as much time with their parents, they may have extra chores and they don't know what to expect from one day to the next.

- **Embarrassment:** Siblings of a child with cancer may feel embarrassed because their brother or sister looks different or because their family has changed. They may not want to tell anyone that someone in the family has cancer, or they may not want to be seen with their sick brother or sister at school or in public.

Oliver's Story: For "Sibs" of Kids with Cancer **is scheduled to be released in July.** Please watch for the announcement on our website or call the national office for details. One free soft-cover copy is available to families of children with cancer. Additional copies (both hard cover and soft cover) are available for purchase through our website store.

Once again, our deepest gratitude is expressed to the Davenport Family Foundation for providing the necessary funds for the printing of this essential resource. Their continued support of children with cancer in this country has positively impacted thousands of children's lives. Heart-felt appreciation is also extended to Computer Associates for their corporate support of this publication's release.

Parents can contact Candlelighters National Office at:
1-800-366-2223
or visit our website at:
www.candlelighters.org
to receive a free copy.

“Sacred Love Tour 2004” Chooses Candlelighters

As Concert’s Charity of Choice

Sacred Love Tour 2004 featuring **STING** and **ANNIE LENNOX**, two of the world’s most talented and beloved performers have chosen Candlelighters Childhood Cancer Foundation’s National office as their national tour’s Charity of Choice!

STING and ANNIE LENNOX will be performing together in Amphitheatres and arenas throughout the summer, starting on June 27th at the Tweeter Center in Philadelphia. Candlelighters will be receiving donations from those attending the concerts across the country, with donations supporting our programs for children with cancer and their families.

As a musician, Sting has remained at the forefront of public consciousness for more than two decades and has written some of the most enduring songs of our time. His latest recording, **Sacred Love**, was released in September 2003. In addition to having released his 10th solo album, Sting has also published his memoirs, entitled Broken Music. The memoirs have remained on various bestsellers’ lists since its recent release. In addition to his music which has touched the lives of millions of people, STING has been regarded as a supporter of human rights causes. Together with his wife, Trudie Styler, they have raised more than $18 million in support of protection of our world’s rainforests. Last month, Sting was presented with the prestigious “Person of the Year” Award by the MusiCares Foundation. In 2003, Sting was also named Billboard’s Century Award Honoree as recognized at the Billboard Music Awards. He’s been awarded 16 Grammys, two Brits, a Golden Globe, an Emmy and received three Oscar nominations. He has also appeared in more than 10 films and starred in the Broadway play “The Three Penny Opera.”

Annie Lennox, three-time Grammy winner and 2002 Billboard Century Award Winner including recent Oscar and Golden Globe wins for “Into The West” from the blockbuster motion picture “Lord Of The Rings: Return of the King” also supports humanitarian endeavors. She is an Ambassador for Amnesty International, Greenpeace, Global Vision for Peace, and the United Nations. She also plays a large role in Nelson Mandela’s Aids Foundation. Annie’s career has spanned two and a half decades, emerging onto the world stage in 1982 with Dave Stewart, her partner in Eurythmics. The duo released their first smash hit “Sweet Dreams Are Made of This” in 1982 and since then Lennox has continuously produced songs that have become part of the soundtrack of our collective lives.

Together in concert this summer, Annie Lennox and STING have chosen to support the littlest cancer children in the country through their support of Candlelighters’ national office.

We encourage families to join the Sacred Love Tour and donate to Candlelighters at the door. Attend a concert in your area and tell families and friends about it too.

Information on concert times and locations are available on Annie Lennox and STING’S website:
(**www.annie-lennox.com; www.sting.com**) as well as
Candlelighters’ website
(**www.candlelighters.org**).

Tickets may be purchased through **www.ticketmaster.com**.

because kids can’t fight cancer alone!

Candlelighters is grateful to STING and Annie Lennox for their support in the fight against childhood canncer!

* * *

Unwanted vehicle? Donate it to Candlelighters for a tax deduction and help cancer kids at the same time!

Are you thinking of selling or trading that old car, boat, or RV? Why not donate it instead? Candlelighters has partnered with Car Program, LLC to provide an easy-to-use, tax-deductible process to donate your vehicle. As a charitable contribution, your donation could make a big difference to children with cancer across the country.

To get started, all you have to do is fill out the form on our website **(www.candlelighters.org)** by clicking on the Donation’s link), then Donate-a-Car’s towing company and customer service department will contact you via telephone within four business days at the latest. If you would like more information, there is a link on our website which provides answers to frequently asked questions. Any further questions can be answered prior to initiating the donation process by emailing Donate-a-Car at: **info@carprogram.com**

Congressional Hill Updates

Update on Oral Cancer Demonstration Project in the Medicare bill

On December 8, 2003, the President signed into law the Medicare Prescription Drug, Modernization, and Improvement Act, which will for the first time provide seniors in America with a voluntary, comprehensive prescription drug benefit. Full implementation of the benefit will begin in 2006. However, Rep. Deborah Pryce (OH) and Sen. Olympia Snowe (ME) secured a provision in the new law to provide transitional coverage for oral cancer drugs before the benefit is available in 2006. Currently, Medicare does not cover oral cancer drugs that do not have an injectable counterpart.

The transitional benefit will be administered through a demonstration project by the Centers for Medicare and Medicaid Services (CMS). Specifically, the legislation provides $500 million to be split between covering oral cancer drugs and self-injected biologics. The report language accompanying the legislation encourages the CMS to ensure that at least 40 percent of the $500 million will be spent on oral cancer drugs. Rep. Pryce and Senator Snowe have encouraged CMS to follow this report language. CMS has yet to issue a final decision as to how the benefit will be delivered, but it is expected that the agency will do so soon.

Update on Compassionate Care for Children Act

On October 6, 2003, Representatives Deborah Pryce (OH) and John Murtha (PA), and Senators Mike DeWine (OH) and Christopher Dodd (CT) introduced the **Compassionate Care for Children Act** legislation that would make improvements to the pediatric palliative care system for children with life-threatening illnesses and their families.

Title I of the bill would provide grants to children's hospitals, hospices, and home health agencies to better train and educate professionals who care for sick children. Grants would also be available to start and expand pediatric palliative care programs to provide better care options for children and their families. Finally, grants would be available for pediatric pain and symptom management research.

Title II of the bill would provide changes to the palliative care system with the goal of improving the care children with cancer and other life-threatening illnesses receive. The current health care system does not account for the special needs of children, and requires children and parents to choose between accessing curative or palliative care. Under the Medicare hospice benefit enacted in 1982, a child and his or her family must forgo curative treatment for their child to qualify for hospice care, and that child must also be diagnosed with only six months to live before he or she can access hospice care.

Congresswoman Deborah Pryce with Rose Ledford

Demonstration projects established under this legislation would waive those requirements under Medicare, and allow children to have access to a full range of care options that most appropriately meet their needs. Should these demonstration projects prove successful in giving children improved access to specialized and tailored care, the Medicaid program, which covers a significant number of children, as well as the private sector are expected to follow.

Sponsors in both the House and Senate continue to work to gain support from their colleagues for cosponsoring the legislation (H.R. 3127 in the House and S. 1629 in the Senate).

Additionally, report language was included in the Medicare Prescription Drug, Modernization, and Improvement Act that directs the Secretary of Health and Human Services to conduct demonstration projects to determine whether palliative care for children may be improved under circumstances where barriers are reduced or eliminated. This language is based off of Title II of the Compassionate Care for Children Act. The Centers for Medicare and Medicaid Services (CMS) is in the process of determining how this demonstration project could be administered.

> **"Of all forms of inequity, injustice in health care is the most shocking and inhumane." Rev. Martin Luther King Jr.**

Family Medical Leave Act continued

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member of the family to take more than 12 weeks of the allotted unpaid leave. As a result, many young families with a chronically ill child face loss of pay for weeks and months at a time, potential loss of employment, and even personal bankruptcy as a result of caring for their cancer child. It is because of this inconsistent and untenable mix of the current federal US employment policy and family health care needs that organizations such as Candlelighters have joined together with other organizations to advocate for a national paid family leave policy.

Background

Each year in the United States, approximately 12,400 children under the age of 20 are diagnosed with cancer.[1] One in 300 children is diagnosed with cancer before they complete their adolescent years. Standard cancer treatments (without complications such as relapsed disease), lasts from one to three years depending on the cancer diagnosis. End result—at any given time in the U.S., there are approximately 30,000 children on active cancer treatment.

In the last thirty five years, the cure rate for childhood cancer has jumped from 10% to 70%. Currently, one in 640 young adults under the age of 39 is a survivor of childhood cancer and it is estimated that by the year 2010, that number will be as high as 1 in 400.[2] Despite the increased number of cures, childhood cancer remains the number one disease killer of children under the age of 15. While survival rates have improved drastically, so has the focus on long-term side effects (after-effects) of treatment. Those who do survive often face lifelong complications from the treatment of their disease. Treatment for childhood cancer is aggressive, often with a combination of chemotherapy, radiation, and surgery. Children receiving cancer therapy are treated at a time in their life when they have a growing body and developing brain. Such exposure to toxic cancer therapy results in extensive damage to the tissue and organs of the child on active treatment. Recent studies have shown that the majority of survivors have some late effects resulting from treatment, with approximately 30% of those late effects classified as moderate to severe.[3] Long term impairments may include cognitive deficits, endocrine dysfunction, cardiomyopathy, seizures, stroke, peripheral nerve dysfunction, chronic fatigue, hearing loss, vision impairment (cataracts), stunted growth, obesity, and secondary malignancies. Depending on the diagnosis and corresponding initial cancer treatments, follow up care resulting from late complications of the cancer treatment can result in the need for the child to continue with extensive health care throughout childhood and into adulthood. A diagnosis of childhood cancer is devastating for the family both financially, emotionally and socially. Extensive time away from work can be required for the cancer child not only during their initial cancer treatment but also in the years to follow.

"Family-Centered Care" as "Standard of Care" for Children Treated for Cancer

The government report entitled "Healthy People 2010" defines family-centered care as "recognizing that the family is the principal caregiver and the center of strength and support for children. The onset of family-centered care in the pediatric acute care setting was originally built on the premise that parents knew their children best and thus could act as an effective mediator between the child and professional caregivers. In the 1960's, hospital policies typically allowed only parental visits of hospitalized children and only then during limited visiting hours. These policies were replaced in the 1980's with open ended visiting hours for family members, and parents being encouraged to stay with their acutely ill children around the clock. Individual pediatric acute care rooms were redesigned to include sleeper sofas for parents, areas for interactive play, shower facilities in the bathrooms for parental use, in addition to the construction of common rooms for family use including televisions, computers, and cooking facilities. The high costs associated with restructuring pediatric facilities was offset by an increase in patient satisfaction, improvements in patient safety, reduced hospital stays, and a reduction in staff time spent entertaining and comforting sick and unhappy children. Parents felt privileged to be entrusted with playing a role in the decision making process and providing basic care needs for their children. They felt empowered through the regaining back of some sense of control in a situation that otherwise felt to be totally 'out of control.'

The original rationale for family-centered care was to include family members (parents) as a type of 'translator' and social worker—mediating communication between the patient and the medical staff. However in many instances, the 'translator' role was quickly transformed into a clinical services delivery role, where the parents began to participate in the clinical management of their sick child. The involvement of parents in clinical care is perhaps most dramatic in pediatric oncology. Pediatric oncology staff members now educate parents about their child's cancer, treatment regimen, and day to day in-hospital (and out-patient) care needs. "Family-centered care" of the pediatric cancer patient has evolved to the level where parents are providing extensive nursing care for their children both in-hospital and at home.

Financial Burden

The resulting impact for providing extensive clinical type care for a child with cancer is enormous. In addition to the loss of income due to loss of work while caring for the cancer child, the average medical and non-medical costs associated with caring for a child with cancer is prohibitive for most families.

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Family Medical Leave Act continued

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Out-of-pocket medical expenses resulting from pediatric cancer center charges have been shown to average $34,558 over the course of the treatment.[4] The family is often faced with additional non-medical expenditures associated with traveling to and from the treatment institution, accommodation and meals away from home, as well as daycare for other young children at home. These non-medical out-of-pocket expenses associated with providing treatment for the cancer child have been shown to average 38% of the family's gross annual income.[5] As presented above, parental responsibilities in providing clinical care for their cancer child is most often incompatible with full time employment by the parental caregiver(s). The current federal employment laws do not provide for any paid family leave so thus it is typically necessary for the care-giving parent to take extensive leave or quit their job in order to care for their cancer child. As a result, lost wages associated with caring for a cancer child account for nearly half of the two parent family's previous annual income. [6] This financial strain is considerably greater in the single parent family. It is not uncommon for childhood cancer families to lose all assets and emotional stability in the process of providing the best possible care for their child.

Family Medical Leave Act (FMLA)
Paid leave policies which allow time from work to care for oneself when ill are implemented in varying degrees in **all industrialized countries of the world, with the exception of the USA, Australia, and Ethiopia**. In 1971, the National Partnership for Women and Families was founded to promote fairness and equity for women in the workplace. One of the organization's initial major activities was in getting the Pregnancy Discrimination Act (PDA) enacted and implemented. The implementation of the PDA in 1978 prevented firing of a pregnant woman, but did not address the issue of maternity leave—time away from work to care for the newborn child. The National Partnership for Women and Families then joined forces with more than 200 support organizations to pass the Family Medical Leave Act. After an 8-year political struggle, the FMLA was finally passed into law on February 1993, and was the first bill that Bill Clinton signed after becoming President. CFR, Title 29 (Labor), Chapter V (Wage and Hour division, Dept. of Labor, Part 825), The Family and Medical Leave Act of 1993 allows 12 weeks of **unpaid** job protected leave a year due to 1/ parental leave, 2/ care for a seriously ill family member, and 3/ recovery from one's own illness. The eligible employee receiving FMLA leave is guaranteed their own job or similar position upon return to work, maintenance of health benefits while away, and retention of their job seniority.[7] Given the 8-year resistance from business associations towards the passing of the law, the National Partnership for Women and Families had to pick their 'battles' in order to have adequate political support for the passing of the legislation in 1993. Among the compromises in the bill is the 3 month clause permitting leave **without pay**, as well as the enforcement of FMLA solely to companies that employ 50 or more workers, and to workers who have worked for an employer for at least one year and for a minimum of 1250 hours in that year. Because the law applies only to companies employing 50 or more employees, the current law does not cover and protect the 43 percent of the American private sector workforce.[8] Nor does it provide for paid leave, or cover those workers who are in need of more extensive leave(paid or unpaid) for greater than 12 weeks, such as is the case of families who have a child diagnosed with cancer.

It is for this reason that Candlelighters has joined with The National Partnership for Women and Families in their "new battle" —that of wage replacement for employees who are in need of taking family leave. Currently, initiatives to implement family leave **with pay** are being fought on both the federal and state level. With this in mind, as of June 2004, at least 27 states have considered some kind of paid leave legislation. To date, the biggest win has been in California. The current coverage which was signed into law on September 24, 2002, will begin to pay out benefits on July 1st of this year—specifically 55% of wage replacement to a maximum of 6 weeks per year. Economic estimates have convincingly demonstrated that the associated cost of providing this paid wage replacement will be an average of $27.00 per worker per year. **For approximately $27.00 annually, starting July 1st, 2004, families in California (regardless of company size) will be guaranteed 6 weeks of 55% wage replacement if they take time off, or leave their jobs to care for a seriously ill family member—including seriously ill children. Those who are eligible for paid leave are those who already pay into the state disability insurance program (SDI).** As of January 2004, SDI payroll deductions from each paycheck were increased by approximately 0.08%, with a small portion of that increase being used to fund paid family leave. California currently has the most comprehensive paid leave law in existence. While more than half of the states in the country have considered some kind of paid leave policy (fewer have actually passed paid leave laws), even the 'best' coverage that is found in California covers up to a maximum of 6 weeks of partially paid coverage. As discussed, the average length of time that a child requires constant parental care is one and a half years.

On the federal level, Senator Edward Kennedy and Representative Rosa

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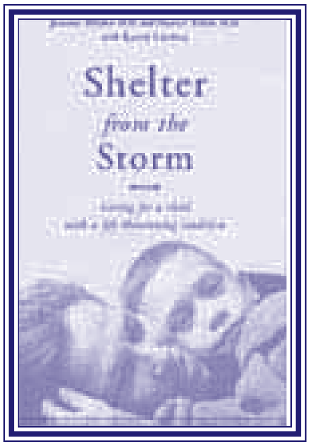
Book: Shelter *from the* Storm



Shelter *from the* Storm provides parents of children with a life-threatening illness or injury, the much needed guidance to address their feelings of grief and hopelessness. Co-authored by Drs. Joanne Hilden MD and Daniel Tobin MD, the book provides information about what to expect during this difficult time in the child's and family's life. "It's always a horribly difficult time, whatever the outcome—the child's suffering and helplessness, the uncertainty, the hopes, the fears," write the authors. Helpful advice is provided on issues such as communication regarding prognosis and treatment, emotional impact on the family members, partnering with the health care team, in addition to suggestions for building lasting memories. Chapters include: Facing Your Child's Life-Threatening Condition, Individuality of Disease, Taking Control of Your Life, Coming to Terms, Your Spiritual Mindset, The Turning Point, Some Needed Preparation, and Finding Peace.

This 220 page book is available through Perseus Publishing.

Family Leave Act continued

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DeLauro introduced the **Healthy Families Act** in June of this year. The Key provisions of the act include **one week paid leave** for full time employees in companies larger than 25 employees. While one week does not provide adequate paid leave time from work for families caring for their children diagnosed with cancer, it does take the necessary step to introduce a national paid leave policy in our country. The time would allow one week of paid leave that could be used at the time of the cancer diagnosis to provide time for the family to set up a support system to assist them during the upcoming months of treatment that lies ahead of them. More information about the Healthy Families Act, as well as template letters to send to local representatives in both the Senate and House can be found on our website **(www.candlelighters.org)** by clicking on the Advocacy link. **We strongly encourage families to take a few moments to write their congressional representatives to ask for their support of this important national legislative initiative.**

Children's Health Insurance Linked to Employment:

As discussed above, many families who have a child treated for cancer may face potential loss of one parent's employment. In addition to the financial and emotional impact that this places upon the family there is the additional complication that in the US, a family's health insurance coverage is typically tied to employment. Recent analysis showed that approximately two-thirds of America's 77 million children receive health coverage through their parent's employer, including 32% of children from low-income families."[9] Even if families do take 12 weeks of unpaid leave from work, they are often forced to return to work after that short time frame in order to maintain their child's health care coverage. For those families who lose their employer-based health insurance due to loss of employment when becoming the primary caregiver for their child, most will be given the option to maintain short term coverage through COBRA (Consolidated Omnibus Budget Reconciliation Act). COBRA eligibility enables the terminated employee to continue health coverage from their previous employer, although the individual must now pick up all payments including those premiums previously paid by the employer. COBRA ensures that health care coverage is not dropped, and is guaranteed by law for those employees and their dependents who were previous beneficiaries under their employer's group health plan, immediately prior to the termination of their job. While **COBRA maintains health coverage for all dependents up to eighteen months,** families or single parents who must use COBRA and have lost one income will find the cost of COBRA coverage financially draining if not prohibitive. **Note that obtaining new health care coverage for a child who has already been diagnosed with cancer is also likely impossible.** Alternative health coverage would also need to be sought for those children whose cancer therapy extends beyond the 18 months coverage allotted through COBRA.

The loss of income will place many families in a significantly reduced income bracket making them potentially eligible to receive health care coverage for their child through the public health insurance programs—SCHIP (State Child Health Insurance Plan) and Medicaid (joint federal and state insurance coverage for the poor). Medicaid and SCHIP are meant to combine to provide America's low income children with publicly funded health care coverage. Currently there are 23 million children receiving health care coverage through these two federal-state funded programs.

SCHIP provides health care coverage for children of middle class families with incomes above the levels that would disqualify them for Medicaid. Like Medicaid, there is state flexibility in determining income eligibility and a few

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Study Announcement: ALTE02C1

Quality of Life in Children Who Survived Neuroblastoma

As all families know who have had a child with cancer, the overarching goal for the parents and treatment team is to cure the disease. However, despite the very difficult and lengthy treatments that many children with cancer must undergo, surprisingly little information exists on the long-term effects from childhood cancer and its treatment, among those who are fortunate enough to survive. Even less information is known about the long-term impact of the cancer experience on the child's parents and on family functioning. Dr. James Gurney, a research epidemiologist and associate professor in the Department of Pediatrics at the University of Minnesota, is leading a study to learn about some of the long-term effects from neuroblastoma, and how these effects differ depending on the type of treatment the child received. Neuroblastoma is a rare childhood malignancy of the sympathetic nervous system that often arises from the adrenal gland, but can first occur in many other areas of the body. Depending on the stage and risk level of the disease at diagnosis, treatment options range from surgery only, to intensive chemotherapy with stem cell (bone marrow) transplantation.

The goals of Dr. Gurney's follow-up questionnaire study are: 1) to evaluate quality of life and medical late effects among long-term survivors of neuroblastoma; 2) to assess family impact from neuroblastoma and how family impact is associated with the child's quality of life; and, 3) to compare differences in these outcomes according to the treatment the child received. For parents and their child to be eligible to participate in the study, 1) the child had to be enrolled and treated on one of two Children's Cancer Group protocols: CCG 3891 or CCG 3881; 2) the child must still be living and not currently undergoing any cancer treatment; 3) at least one parent and the child must be able to read and write English; and 4) the child must be 18 years of age or younger when the questionnaire is completed. The study requires the child to fill out a short questionnaire, and one or both parents to complete a questionnaire. If your child was treated for neuroblastoma and enrolled in one of these two protocols at a hospital that was affiliated with the Children's Cancer Group, you may be eligible to participate. If you would like more information, you can contact Dr. Gurney at 612-624-5178 or email him at gurney@epi.umn.edu.

Major funding for this study was provided by the American Cancer Society.

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Purchase Your Angel Bear at Candlelighters Website Store

Visit www.candlelighters.org to purchase your angel bear and other childhood cancer items. 100% of the proceeds will be directed back into the programs and services offered by our organization. Every $10.00 raised through our webstore sales, puts a book into the hands of a child who has been diagnosed with cancer.

- Angel Bear: $9.95 each
- Lapel Pins: $2.50 each
- Vehicle Magnets: $5.00 each

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http://groups.yahoo.com/group/CandlelightersNational

Family Medical Leave Act continued

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states have adopted levels as high as 300% of the federal poverty level (FPL). Unfortunately, a specific requirement of SCHIP results in disqualifying many of the families who need it most. Specifically, children must be uninsured for one to six months prior to enrollment. Thus, the parent of an ill child who has left his/her job to care for their cancer child must drop any existing health insurance for 6 months prior to coverage by SCHIP. There are only two options for the six months; either the parents must incur all charges personally, and face possible personal bankruptcy, or halt treatment for 6 months. While most families are able to 'plead their case' and have SCHIP coverage be established, there is the possibility in today's budget strapped states that this will not continue to be the case. It is imperative that amendments be made to the existing eligibility criteria for SCHIP that accommodates catastrophic illnesses such as an existing diagnosis of childhood cancer.

If we focus on those families who are eligible for Medicaid, the many rules and regulations concerning age-dependent eligibility serve to continue to exclude families from coverage, rather than providing an inclusive safety net. Medicaid was created in 1965 as a federal-state initiative to provide comprehensive health care for our nation's poor. Medicaid currently provides coverage for approximately 20 million children in the US. Eligibility is based upon the child's family meeting the state's definition of low income. This amount is variable by state and, like SCHIP, is linked to the federal poverty level. While most states have extended coverage for children to 200% of FPL, federal guidelines also link income eligibility to the FPL by age of the child. The minimum requirement level set by the federal government to cover children from birth to age five (inclusive) is 133% of the FPL. In contrast, the minimum threshold set by the federal government to cover children from age six to eighteen is 100% FPL.[10] Thus, in states where qualification is linked 100 percent to the federal poverty level, a child who is diagnosed with leukemia at the age of three, whose parent's income was calculated to be less than 133% of FPL would qualify for Medicaid coverage as mandated by the Federal Guidelines. The same child diagnosed at age 6 would not be guaranteed coverage as mandated by the federal government. Similarly, a child who is diagnosed with cancer at age five could be covered for the first year of treatment, and then potentially fail to re-qualify during their annual review after the child had turned six years of age. While the majority of states have opted to provide Medicaid coverage to all children from birth to age 18 to at least 133% of the federal poverty level, there is concern that states again will address their huge budget deficits by reducing Medicaid spending through the return of eligibility requirements to the minimal thresholds imposed by the federal government.

Another Medicaid eligibility provision in danger of being threatened because of budget deficits is the Presumptive Eligibility Clause. Through this provision, children who are diagnosed with an illness and in need of immediate treatment, receive prompt coverage based upon the "presumption" that they would be eligible for coverage once the application process is complete. This clause allows the family the necessary time to collect the required documents and receive approval for coverage, while ensuring that the child is not denied necessary health care in the interim. As of April 2003, 8 states had implemented the presumptive eligibility provision.[11] Forty two states have not implemented this provision. It also must be noted that most states require proof of reported income as an essential document for eligibility. In the case of the family who has experienced a recent change in income due to the loss of one income resulting from one parent taking extensive leave from work, their previous year's income tax filing would not reflect their current income status. Thus there is potential for denial of coverage in those states where a family's financial status is strictly enforced through the use of previously reported official income tax submissions.

The one effective piece of legislation that positively assists the family in need of health care coverage for their cancer child is referred to as the Katie Beckett waiver. Created in 1982, this legislation was enacted as an incentive for parents to provide home care for their disabled child, as an alternative to costly institutional care. Unlike Medicaid which is based upon a family's proof of low income status, this waiver provides families with comprehensive Medicaid coverage for severely disabled children, without consideration of the family's income level. To qualify the child must meet the Social Security criteria for "disabled," and must be receiving home medical care that otherwise would be provided through an institutional stay of at least 30 days.[12] Full Medicaid coverage including home care assistance is provided through the Katie Beckett waiver. This public insurance program is considered to be the best option for providing comprehensive coverage of cancer children receiving very aggressive treatment. Unfortunately, this program is not well known and subsequently not well utilized by the pediatric cancer population and also is in potential danger of being cut in many states as a result of massive state budget deficits.

Proposed Amendments to Existing Employment and Health Care Policies

As discussed above, the family faced with the responsibility of caring for a severely ill child, such as the diagnosis of childhood cancer, is currently "between a rock and a hard place." Their child is in need of direct parental care while at the same time, parents are unable to receive paid medical leave from employment to provide that care. If the parent does quit their job and were

Continued on page 10

Family Medical Leave Act continued

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the source of health insurance coverage for their child through that employment, then the child's health care coverage is put at risk, in addition to the family's financial stability.

The political climate is ripe for federal implementation of a paid leave policy as an expansion piece to the existing FMLA or as a separate Bill such as was recently introduced by Senator Kennedy and Representative DeLauro. A recent survey by the National Partnership for Women and Families revealed the following:

- 82% of employees aged 18-34 say they support expanding the FMLA to provide paid leave.
- 89% of parents and 84% of all adults say they support expanding unemployment insurance or disability insurance as a vehicle for paid leave.
- 79% of working women believe access to paid family leave is more important than increased pay, promotions and job flexibility.
- Worker's number one career concern is finding time for family.[13]

Never is there a greater need for reform of the current policy regarding family paid leave than in the case of a child diagnosed with a life-threatening illness.

The following are suggested areas for positive change with regards to family leave and associated health care policy.

- Passing of Healthy Families Act 2004 to implement one week paid leave for individuals employed in companies with greater than 25 employees.
- Passing of amendment to the existing FMLA legislation to include federally mandated paid leave provision for all employees regardless of company size.
- Creation of state based short term disability programs similar to California's Temporary Disability Insurance that would include paid leave to care for dependent children, with maximum time allotment linked to the child's diagnosis and care requirements.
- Creation of employee based medical leave 'pool' that would allow employees to donate personal paid leave benefits to another employee in need.
- Increase income eligibility criteria of SCHIP to 300% FPL in all states (regardless of age of child), and eliminate requirement for the child to be uninsured for one to six months prior to eligibility for those children with pre-existing catastrophic health care needs due to loss of parent's employee based health care coverage.
- Government funding assistance to families to offset the high premium costs to maintain COBRA coverage for acutely ill dependents. Extension of COBRA coverage (greater than 18 months) to correspond to the child's diagnosis and treatment protocol.
- Establishment of outpatient treatment facilities which remain open 'after hours' to enable parents to work during the day and pursue outpatient therapy for their child in the evenings and on weekends.
- Increase awareness and availability of Katie Beckett Medicaid coverage for children diagnosed with cancer.
- Expansion piece to existing SCHIP legislation to include presumptive eligibility for catastrophic childhood illnesses.

Conclusion

The increased responsibilities associated with providing family-centered care for the cancer child results in extensive time commitment and economic impact upon the family. As families of children with cancer, we are our children's voice. Your support of congressional initiatives such as the Healthy Families Act assists families whose children are currently on treatment for cancer and those families in the future who will walk down this same road. **Please consider taking time to fax or mail your member of Congress to ask them to support the Healthy Families Act. Template letters are available on Candlelighters' website www.candlelighters.org by clicking on the Advocacy link, as well as enclosed in this newsletter.**

Citations

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Advocacy and YOU!

Advocacy, lobbying, politics. Why is this important? This issue of the National Journal is devoted, in large part, to advocacy initiatives. Perhaps the best explanation of why we all need to take advocacy for childhood cancer very seriously was described to me by a highly respected senior representative to C-Change from the National Cancer Institute. He said, "The more I think of it, the more I understand why representing children with cancer is so important; they really do not have a voice of their own in this system." Candlelighters National Office represents your voice, and the voiceless children with cancer in this country. But the voice is so much more powerful with numbers, and with "constituency." Your congressional representatives do indeed care about you and your concerns, and they WILL listen. So become an advocate. Become a representative of the voiceless cancer child. Write your member of congress (House and Senate) in support of the **Healthy Families Act**. Convince congress that taking care of these littlest cancer patients requires their parents. We provide a template letter below, and you can find the contact information for your congressional representatives at **http://www.house.gov**, and **http://www.senate.gov**. Letters are particularly effective when they contain your personal story. We also have the following letter as a downloadable word file at our website **(www.candlelighters.org)**; just click on the Advocacy link. Help us help these kids.

...Because kids can't beat cancer alone!

Dear

We are writing as members of your constituency to **request your support for the "Healthy Families Act"—**a bill that was introduced by Senator Kennedy and Representative DeLauro to help working Americans and their families deal with pressing medical needs while maintaining economic stability. "The Healthy Families Act" provides full-time employees with **7 days of paid leave** a year to be used for their own medical needs or to tend to the medical needs of a child, spouse or parent. Part-time employees receive a pro-rata share of paid sick leave.

As one of thousands of families who learn each year that their child has been diagnosed with cancer, we personally found ourselves dealing with the horrible dilemma of needing to take extensive time from work without pay, to care for our acutely ill child. Children cannot undergo cancer treatments alone! **Most often a parent must forego their paycheck while caring for their child who is receiving cancer therapy**. Too many families face personal financial ruin in addition to the trauma of caring for their cancer child. While some families in this country are fortunate to work for employers who provide paid family leave, almost half (47%) of the private sector workforce, including private sector working families of children with cancer have no paid leave. Lower wage workers are particularly vulnerable: over three in four (76%) of workers in the lower quarter in earnings have no paid leave, and among working parents with incomes below 200% of the federal poverty line, 41% have no paid leave of any kind.

While one week paid leave will not be sufficient time to provide family-centered care for the entire duration of a cancer child's treatment regimen, it will provide time for families to build a support network of friends and extended family members to assist them during their child's treatment.

Creating a work environment that helps employees better balance the responsibilities of work and family not only helps families such as ours, but also benefits employers by increasing work productivity and reducing employee turnover. Offering workers the option of taking time off when a family member is sick affects profits positively, according to a 2001 study published in the *Journal of Managerial Issues*.

With full congressional support of this important initiative, our country can proudly say that we provide paid leave for America's working families! Thank you for your support of this important bill.

Sincerely,

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

The Candlelighters Childhood Cancer Foundation is a national 501(c) (3) non-profit membership organization whose mission is to educate, support, serve and advocate for families of children with cancer, survivors of childhood cancer and the professionals who care for them. IRS# 52-1071826

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Ruth Hoffman, *Executive Director*
Director of Publications

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.

Please send correspondence to:
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****Due to a high number of email viruses, we changed our address. Please note the new email address.****

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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 to read the latest edition of our national journal, new publications, current childhood cancer information and membership form.
http://www.candlelighters.org

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

> **"There are 2 ways to spread light; to be the candle or the mirror that reflects it."**