CANDLELIGHTERS
CHILDHOOD •CANCER •FOUNDATION

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The Quarterly Newsletter

MARCH 2000

PRACTICAL GENETICS IN CANCER

First of three parts *by Eric P. Hoffman PhD*

Included in the next edition of

The Quarterly

- *Long Term Follow Up Care: Why is it needed?*
- *Practical Genetics in Cancer: Part II*
- *Oversight of Gene Therapy Trials: Is it working?*

Inside this issue:

PRACTICAL GENETICS IN CANCER: The Human Genetic Code

by Eric P. Hoffman PhD

Pediatric cancer families are more and more frequently presented with genetic information regarding their child's disease. The genetic tests can sometimes hold important diagnostic and prognostic information. Genetic technology is continuing to develop extremely rapidly; for example the NIH has recently announced a program to provide a series of $8 million grants to use "gene microchips" to help diagnose cancer patients, and provide information on the likely responsiveness of specific patients to types of cancer therapy. This new type of large scale "genetic informatics" is expected to have a dramatic effect on how pediatric cancer patients are diagnosed, and treated.

This is the first of a series of "primers" that hope to help provide an understanding of current and future applications of gene technology to the diagnosis and care of children with cancer. This first article provides some perspective with regards to the genetic code of humans, and how this is frequently altered such that tumors result. The second installment will speak to current genetic tests in pediatric oncology patients, and what the results of these tests mean.

The Human Genome
23 Chromosomes

The last contribution will describe emerging high-tech methods which are being developed to provide "molecular fingerprints" of each child's tumor, and how this will likely effect treatment of childhood cancer in the near future.

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Summer Camp Registration

Fireflies, campfire, swimming, canoeing, games, crafts and laughter are summertime fun activities that are only a few months away. Registration for children's cancer camps have just begun.

For a list of children's oncology camps in your state, call the **Candlelighter office at: 1-800-366-CCCF email info@candlelighters.org**

Alternatively, call **COCA** (Children's Oncology Camping Association) at: **800-737-2667** or visit their website at: **http://www.COCA-intl.org** or visit **http://www.acor.org/ped-onc/cfissues/camps.html**

Register your child for a camping experience like no other, with memories made that will be cherished forever.

Letter from the Director:

As Candlelighters enters the twenty first century, it will be our 30th year of providing services to families whose children are diagnosed with cancer. Our mission has been to educate, support, serve and advocate for children with cancer, their families, survivors of childhood cancer and the professionals who care for them. There have been many transitions made over those past thirty years with the most recent changes resulting from severing the ties with the American Cancer Society in 1998. Families were asked to provide input into this decision and the Board concluded that Candlelighters' mission was better served as an independent organization. It was concluded that childhood cancer had unique needs when compared to adult cancers and as a result required the sole focus of an organization to meet those special needs. Children are diagnosed with different types of cancer than adults. The management of their treatment is different, as is the day to day impact upon the family while caring for the young child with cancer.

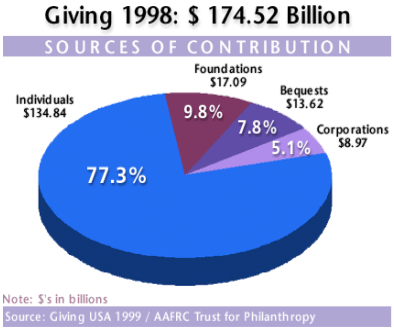
As an example of the "need" for Candlelighter's services, let me recount a week's worth of activities: sent out 238 books (including a newly released publication), responded to 127 phone calls, answered 96 emails (patients, families, group leaders, board members), sent 20 letters in response to donations, updated the mailing database with 240 address changes and new members, gave a talk to George Washington film students who are doing a public service announcement for us, and attended the Senate hearings on gene therapy oversight in clinical trials.

The break with the ACS has forced Candlelighters to become a "lean machine". In the past five months, we have moved operations out of an eight room office suite in a prime rent district in suburban DC, into donated office space one quarter the size. We have gone from five paid staff members, down to a single part time employee. The result has been a reduction in the annual operating budget by over 50%. In spite of this decrease, we are sending newsletters for the first time in 2 yrs, releasing new publications, reformatting and expanding web sites, while continuing to offer services via our 1-800 number and email.

Candlelighter's national office is used by hundreds of families and patients desperate for information and help. All services, including publications, are provided free of charge. Obviously, we can not do this without donations to keep the operation running. It is often assumed that most non-profits are largely funded by "corporate money". However, as shown in the pie chart below, from "Giving USA, 1999", only 5% of non-profit funding comes from corporate donations. Comparatively, 77% comes from individual contributions. Your gift does indeed make a huge difference. A mere $10 donation made by each person receiving this newsletter would result in the needed operating budget of the national office for the entire next year.

Thanking you for your continued support.

..Because Kids Can't Fight Cancer Alone



CONTACT INFORMATION

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***Website:* http://www.candlelighters.org**
***Email:* info@candlelighters.org**
Ruth Hoffman, *Executive Director*
& Newsletter Editor

In-Memorial Donations

Candlelighters would like to thank those who made donations in memory and honor of the following loved ones.
June 1, 1999 – February 1, 2000

Bradford Lambert
Lisa Shulman
Michael Sullivan
Rebecca Sherron
Casey Wax
Nelson Wax
Rebecca Palley
Vincent Grimes
Ruth Laughlin
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Colin _
Peter Rooney

…I am standing upon the seashore. A ship at my side spreads her white sails to the morning breeze and starts for the blue ocean. She is an object of beauty and strength and I stand and watch her until at length she hangs like a speck of white cloud just where the sea and sky come down to mingle with each other. Then someone at my side says: "There! She's gone."

Gone where? Gone from my sight – that is all. She is just as large in mast and hull and spar as she was when she left my side, and just as able to bear her load of living freight to the place of destination. Her diminished size is in me, not in her; and just at the moment when someone at my side says, "There! She's gone," there are other eyes watching her coming and other voices ready to take up the glad shout, "There she comes! Author unknown

Second Malignancies?

by Nancy Keene and Kevin Oeffinger M.D.

Some survivors of childhood cancer worry that they will get a second cancer. Others think that lightening won't strike twice. The chance of developing a second cancer depends on a number of factors including your original type of cancer, age at diagnosis, gender, types of therapy given, environmental exposures, genetic predisposition, and health decisions. Overall, for most survivors the chance of getting a second cancer is very small.

The information in this article is meant to make you aware, not concerned. There is no reason to be fearful about getting initial treatment that has the potential to cure the cancer because of the very small chance that you may get a second cancer.

You can use the information presented here to spark discussion with your doctor about your individual risk (if any). That knowledge can help you make healthy choices and get appropriate follow-up care to give you the best chance for a long and healthy life.

Genetic risk

Cancers with known genetic causes sometimes carry a higher risk of second cancers. For instance, survivors of familial (inherited) cancers like bilateral retinoblastoma tumor should be evaluated regularly for the rest of their lives because they have a much higher chance of developing second tumors than do other survivors. In some cases, specific genes have been identified that increase the risk of second cancers.

Survivors of Hodgkin's disease, ovarian cancer, the inherited form of retinoblastoma, and the genetic form of Wilms tumor (extremely rare) are at increased risk for second cancers. Persons with genetic diseases such as von Recklinghausen's neurofibromatosis, xeroderma pigmentosum, Klinefelter's disease, Bloom's syndrome, and immunodeficiency syndromes also carry an increased risk of cancer.

If you are in one of the above groups, your follow-up care should be especially vigilant. This allows for earlier detection and treatment should you develop another cancer. It also gives you the opportunity to discuss ways to lower your risks by making healthy lifestyle and behavior choices.

Radiation

Radiation kills cancer cells and also may cause changes in normal cells. In some cases, second cancers develop in the areas irradiated. For instance, Hodgkin's survivors who had mantle radiation have a higher risk of developing breast or lung cancer at a young age and leukemia survivors treated with cranial radiation have a small risk of developing brain tumors. In addition, some radiation (called "scatter") escapes into the areas surrounding the radiation field. Survivors who had radiation to the head or chest can develop late effects in the thyroid gland or salivary glands from scatter radiation. These areas as well as the radiation field should be routinely evaluated during follow-up appointments. In general, the higher the dose of radiation you received, the greater your risk of developing a second cancer.

Chemotherapy

Several chemotherapy drugs are associated with second cancers in some survivors. Examples of these are:

- Alkylating agents—procarbazine, chlorambucil, BCNU, nitrogen mustard,

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  – (Cytoxan), ifosfamide. High doses of these drugs can cause malfunction of bone marrow causing abnormal cells (myelodysplastic syndrome) or acute myelocytic leukemia (AML).

  – Epipodophyllotoxins—VP-16 (etoposide), VM-26 (teniposide). These drugs cause acute myelocytic leukemia (AML) in a small number of survivors.

  – Platinum analogs—cisplatin, carboplatinum. The research is not clear concerning second cancers after treatment with these drugs. Most AML or myelodysplastic syndromes occur when the platinum drug is given in conjunction with alkylating agents or epipodophyllotoxins.

Secondary leukemias that occur in those treated with alkylating agents and/or epipodophyllotoxins are usually seen in the first ten years after treatment. Solid tumors tend to occur many years or decades after treatment ends.

> For most survivors the chance of getting a second cancer is very small.

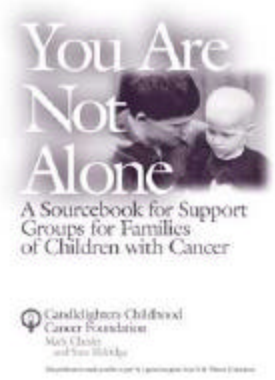
Needed: Participants for a research study on parental coping…..

The University of Maryland School of Nursing is actively recruiting parents of children with cancer for a research study aimed at increasing knowledge of parental coping skills. For participation, the parents must understand English, and their child must be on active treatment. Participation involves filling out a consent form, and questionnaires. These will be sent to those wishing to participate, with a self-addressed stamped envelope for return. The study will be the focus of a Ph.D. thesis in nursing.

Those wishing to assist with this important study should contact:

Anne Belcher, RN, Ph.D.; Supervisor
Phone: 410-706-7407, or
Ms. Hae-Ra Han, Ph.D. candidate
Phone: 410-706-1799

Candlelighters New Publication Now Available



Candlelighters' new Publication is funded by a generous grant from the ***Arthur K. Watson Charitable Trust.***

YOU ARE NOT ALONE:
A Sourcebook for Support Groups for Families of Children with Cancer.

YOU ARE NOT ALONE is written for parents of children who are interested in starting, leading, improving or just being a part of a mutual support group. It also is useful for medical and social work professionals who are interested in helping parents organize such groups. It is presented in a spiral bound format so materials can be easily copied for local use.

YOU ARE NOT ALONE addresses the following issues: what challenges do parents of children with cancer face; how can mutual support groups be helpful to parents in meeting these challenges; what steps are involved in forming a new group; what kinds of programs or services can groups offer parents; what skills do people need to keep a group running efficiently; how formally should a local group be structured; how can groups work best with the medical staff and other community organizations; where can group leaders go for more assistance; and what is the role of the National Candlelighters Childhood Cancer Foundation.

You Are Not Alone is available without charge to families of children with cancer, including all local Candlelighter parent support groups.
To receive your copy:
Email: info@candlelighters.org
or call: 1-800-366-CCCF

Cost to other interested groups is: $15

Book Review:

by Cheryl Tobias

Beating Cancer with Nutrition
Patrick Quillin, Ph.D., R.D.
with Noreen Quillin
Nutrition Times Press, Inc.
Revised Edition 1998
paper back
available in the US public library

Invaluable information, quick and easy to read for a busy parent.

Offers proper diet and supplements to improve quality and quantity of life including the chance for a complete remission.

Topics: malnutrition, reducing toxicity of medical treatment, bolstering immune functions, starving the cancer, preventing and reversing cancer with nutrients.

Program works along with conventional treatments.

Our young adult daughter is enjoying excellent health as she seriously practices alternative therapies.

Cheryl Tobias
Buffalo, New York
mom to Shoshana
5 year survivor of osteosarcoma

Study: Avoiding vitamins A, E might improve cancer therapy

CHAPEL HILL - Vitamins A and E, which normally boost human health in numerous ways, also appear to keep cancer cells from dying through the natural protective process scientists call apoptosis, new University of North Carolina at Chapel Hill research shows.

As a result, giving patients those vitamins may prevent cancer cells from self-destructing and work against cancer therapy, scientists say.

The scientist and his colleagues study reactive oxygen species (ROS), which play a central role in the series of signals that allow cells to kill bacteria and viruses, destroy toxins and trigger the apototic "suicide" of defective cells such as cancer, he said. Antioxidants, such as vitamins A and E, protect normal cells from the damaging effects of ROS but apparently also can prevent the targeted apoptotic death of cancer cells that threaten humans and other mammals, the new work suggests.

"These new studies raise important issues regarding the advisability of ingesting high levels of antioxidants as a potential anti-cancer benefit," Albright said.

Clearly, more studies are needed at the clinical level in human populations to address the real value of antioxidant supplements or antioxidant depletion in people at risk of developing cancer."

David Williamson
University of North Carolina
at Chapel Hill
http://www.eurekalert.org/releases/uncc-sav121399.html

Your Child and the Individualized Education Program (IEP)

by Ruth Hoffman

Candlelighters national office receives numerous calls each week from parents whose children appear to be experiencing learning difficulties at school, as a late effect from their cancer treatment. A variety of learning problems have been correlated with brain trauma as a result of cancer treatment, particularly for brain tumors (radiation and/or surgery), and also high dose methotrexate – a chemotherapy treatment, often used in the treatment of ALL. Parents wish to know how they can obtain special education for their child. The federal government has mandated formalized educational programs for special needs children, called "IEP" (Individualized Education Program). This feature article will lead parents through the steps required to take advantage of this federal program.

Special education is instruction that is specially designed to meet the special needs of children who have disabilities. These may include the disabilities that are associated with the late effects of childhood cancer treatment. The definition of special education comes from the Individuals with Disabilities Act (IDEA), Public Law 105-17. This law lists 13 different categories under which a child may be found eligible for special education services. Many of these categories can include after effects from cancer therapy, including hearing impairment, specific learning disabilities (such as short term memory problems that are sometimes associated with high dose methotrexate treatment), visual impairment (e.g. retinoblastoma), as well as traumatic brain injury. According to the IDEA, the disability must affect the child's educational performance in order to qualify for an IEP.

The first step to find out if your child has a disability is to ask the school to do an evaluation. The school does not have to evaluate your child just because you asked them to, but if they do refuse to do so, they must notify you in writing of this decision and also indicate why your request was refused. If this occurs, you can respond by asking the school system for information about its special education policies as well as parental rights to disagree. Ask for specific steps that parents can take to challenge this decision. Secondly, get in touch with your state's Parent Training and Information (PIT) center. This valuable resource provides information on special education, rights, responsibilities and the law. A listing of the State PTI information is available on the State Resource Sheet, obtained by contacting the National Information Center for Children and Youth with Disabilities (NICHCY) at: 1-800-695-0285. If the school requests that your child be evaluated, because of a concern that your child has a disability, then the school must evaluate your child at no cost to you. Before proceeding, the school must ask for your informed written consent. You, as a parent are entitled to be part of this evaluation process as are individuals such as psychologists that are invited to the process by either you or the school. If the school is not equipped with required qualified specialists such as speech therapists or other medical specialists, then the school must make the arrangements to have the child evaluated outside of the school. Again, all of these evaluation procedures are to be completed without cost to the family. Note that under IDEA, a child may NOT be found eligible for services if the determining factor is due to the child having limited English proficiency or due to a lack of previous instruction in math or reading. Time away from school due to cancer treatment does not qualify your child as having a special disability requiring special education, according to IDEA classification guidelines.

After evaluation is complete and your child is found to be eligible for special education, then the next step is to write what is known as an Individualized Education Program – or what is referred to as an IEP. This must be done within 30 days of completion of the evaluation. The IEP will involve a team of individuals who will work towards the following two general aims: 1/ to set reasonable learning goals for your child and 2/ to state the services that the school district will provide for your child. The focus of the IEP will be on methods available to facilitate learning of the general curriculum as much as possible. Most IEP program place an emphasis on integration of the child into as many regular classes and activities in the school as possible, with special attention placed on enhancing the child's productivity in this environment. Specifically, the IEP will include: 1/ current levels of educational performance 2/ annual goals; 3/ special education and related services to be provided; 4/ participation with non-disabled children; 5/ participation in state and district-wide assessments; 6/ dates and location when services are to begin and where and how often they will be provided; 7/ any transition services needed and finally 8/ a measurement of success evaluation and regular communication plan informing you as the parent.

Related services that might be provided are listed in the IDEA. They include but are not limited to: transportation, speech-language pathology, auditory services, psychological services, physical therapy, counseling (including parent counseling and training), alternative learning strategies, etc.

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For copies of The Federal regulations concerning Individualized Education Programs (IEPs) contact Candlelighters National office at: 1-800-366-2223 or email info@candlelighters.org or call the National Information Center for Children and Youth with Disabilities at 1-800-695-0285 or visit their website at: www.nichcy.org

The Children's Cancer Awareness Project

by Ruth Hoffman

The Children's Cancer Awareness Project (CCAP) is currently preparing quilts for 'The March on Cancer', a coming-together to fight cancer that will take place in Washington DC in September of this year. This will be the second time that the quilts have collectively been displayed; the first was during "The March" in 1998. At this initial event, over 50 quilts were displayed near the Washington Monument. Coordinators from across the United States and Canada, in addition to celebrities Cindy Crawford and Rosy Geer, were present to unveil the quilts. Each quilt consisted of 50 squares. Each square represented a child diagnosed with cancer and their fight to stay alive. Included on all quilts were several memorial squares, honoring those children who had lost their battle. The idea of creating a children's cancer awareness quilt began with Katherine Cales of South Carolina. Katherine's daughter Tamara is a survivor of Neuroblastoma, Stage IV. She was joined by Tracy Clark. Tracy's daughter Morgan is a survivor of Acute Lymphocytic Leukemia. The project moved forward after many parents, caregivers, and friends of children with cancer contributed to the creation of the initial quilt. Katherine continues her commitment as Chairperson for CCAP. Tracy is acting Co-Chair, treasurer and webmaster.

For those families who are interested in participating in this year's event, the following details are provided to assist you. The focus is on choosing a design that is personal to the cancer child. Either the parent or the child themselves are encouraged to create this quilt memory. If you wish, a photo can be scanned, then ironed on to your square. In keeping with past tradition, the committee would appreciate if the following details were included: child's name, child's date of birth; child's diagnosis; city, state, and if applicable child's date of death. All completed squares should be 8 ½" X 8 ½" inclusive of a one inch border. Suggested materials are light colored muslin, cotton, or lightweight denim. Choosing materials that are durable and long wearing is very important as the quilt will be displayed through all types of weather and will be folded many times over the years. Finished squares can be sent to your state coordinator. To obtain contact information, call your child's local treatment center or email the Children's Cancer Awareness Project at: KCales@aol.com
Alternatively, squares can be mailed to:
Tracey Clark
c/o Maryland's Hospital for Children
Department of Pediatric Oncology
22 South Green St., Rm. N5E16
Baltimore MD 21201
or
Kathy Cales
305 Hopkins Street
Manning SC 29102-2118

Your Child and the Individualized Education Program (IEP) continued...

...continued from page 5

Subsequent to the development of an IEP for your child, a once yearly meeting must be scheduled with you to review your child's progress, with the intent to make any changes as necessary. Requests for review can be made at any time throughout the year. Also, a child who is classified as a special needs child, must be re-evaluated at least every three years. The purpose of this evaluation is to determine if your child continues to be a 'child with a disability' as defined under the law as well as reassess your child's educational needs. It must be noted that the school is not responsible for ensuring that the child reaches the IEP goals. The school is responsible in good faith to provide the services, but the school is not responsible if the goals listed are not achieved.

If there are disagreements or complaints about the handling of the child's IEP, resolution may be achieved by 1/ mediation; 2/ due process or 3/filing of a complaint with the State Education Agency (SEA).

For copies of The Federal regulations concerning Individualized Education Programs (IEPs) contact Candlelighters National office at: 1-800-366-2223 or email info@candlelighters.org or call the National Information Center for Children and Youth with Disabilities at 1-800-695-0285 or visit their website at: www.nichcy.org

Additional resources:

Thompson, Sue. The Source for Non-Verbal Learning Disabilities. East Moline, IL: LinguiSystems, 1997. 1-800-PRO-IDEA.
This publication describes the type of disabilities that are often associated with childhood cancer treatment, giving case histories and practical advice.

Candlelighters' book "Educating the Child with cancer" 1-800-366-CCCF

Copeland DR, et al. Neuropsychologic effects of chemotherapy on children with cancer: a longitudinal study.
J Clin Oncol. 1996 Oct;14(10):2826-35.

Brown RT, et al. Longitudinal Follow-up of the intellectual and academic functioning of children receiving central nervous sytem phrphylactic chemotherapy for Leukemia: A Four Year Final Report.J Dev Behav Pediatr. 1996 Dec;17 (6):392-8.

Butler RW, et al. Neuropsychologic effects of cranial irradiation, intrathecal methotrexate, and systemic methotrexate in childhood cancer.
J Developmental and Behavioral Pediatrics Vol 20 No 5 Oct 1999 pgs 373-77

Brown RT, Sawyer MG, Antoniou G, Toogood I, Rice M; Department of Pediatrics, Medical University of South Carolina, Charleston 29425, USA
Longitudinal follow-up of the intellectual and academic functioning of children receiving central nervous system-prophylactic chemotherapy for leukemia: a four-year final report.
In the longer term, the children who received central nervous system (CNS) chemotherapy experienced greater neurocognitive deficits, particularly in the area of academic achievement, than did the children who did not receive CNS chemotherapy. Specifically, the CNS chemotherapy-treated children scored lower on academic tests of reading at 3 and 4 years after diagnosis. The results suggest that CNS chemotherapy prophylaxis may adversely effect the development of higher-order mental abilities and cognitive skills during the late-effects period and may also impair academic achievement.

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First, for some perspective. The genetic code which makes up all individuals is nothing more than a series of instructions to produce all the components of the body; from the time that the sperm and egg meet, to old age. There is a relatively accurate analogy with regards to the famous kitchen volume, the Joy of Cooking. Both the Joy of Cooking and the human genome consist of a relatively large series of recipes, one after the other, spelled out in code. The Joy of Cooking is considerably more complicated in that 26 letters are used, while the human genome uses only four (G, A, T, and C). As in any alphabet, the letters simply refer to some other meaning; in the case of DNA the letters refer to four specific chemical structures that can be hooked up into chains (as letters are hooked up into words and sentences), G = guanine base, A = adenine base, T = thymine base, C = cytosine base. A typical recipe in the Joy of Cooking contains about 30,000 letters of code, and this is quite similar to the average size of a gene (a recipe for a component of your body). A gene and a recipe are also similar in that they themselves are not particularly useful (you cannot eat a page of the Joy of Cooking), but contain the code to make something; the component of the body that each contains the instructions for producing is called a *protein*.

The entire human genetic code contains about 120,000 genes (3 billion letters), which is equivalent in number of letters and recipes to about 100 volumes of the Joy of Cooking. While this sounds like a fairly large number of recipes for proteins, there are many different parts of the body that change with age, so this is not so surprising. Importantly, it has recently been announced that 90% of this 3 billion letter genetic code will be available this coming Spring of 2000; we will all be able to go to our home computers and click over the entire instructions for a human being, just as you would go look up recipes for a thanksgiving dinner in the Joy of Cooking!

It is quite clear that cancer is the result of problems with this genetic code. There are two groups of genes that are responsible for most cancers, each of which causes a single cell to lose control, and become a tumor in a child, but using different methods. The two groups are "oncogenes" and "tumor suppressors". Oncogenes, as the name implies, are genes which can directly cause cancer. Nobody is "born" with oncogenes; instead there are changes to pre-existing recipes that a single component (protein) of a cell from a normal, healthy part of the body, to something that "changes its function" so that it has a dominant effect on the cell; it effectively tells the cell to grow out of control (become a tumor). An analogy here is "the bad person in the neighborhood"; some one member of a large community loses control of his/her actions, and can wreak considerably destruction within the community. "Tumor suppressors" are like the policemen in the community; they constantly survey the neighborhood for problems, and keep things under control. Tumor suppressors are involved in tumors *when they are missing* from the cell. Thus, oncogenes and tumor suppressors are involved in cancer in *opposite* ways; it is the *presence* of an oncogene protein that causes a tumor, while it is the *absence* of tumor suppressors that leads to cancer. Here it is important to point out the issue of inheritance of cancer in families. Some childhood tumors can be inherited, such as retinoblastoma, although most are isolated "sporadic" cases. The retinoblastoma gene is a "tumor suppressor", and all of us have two copies of the code for this "policeman"; one from our mother, and one from our father. What happens in families with retinoblastoma is that one of the two genes in a retinoblastoma patient is disabled (one policeman in the community instead of two). Generally, half of any component of your body is "enough", and all cells are kept under control. However, a single cell can suddenly lose the *other* retinoblastoma gene due to environmental effects (cosmic rays), or just by chance. This cell has no remaining retinoblastoma protein, and loses all police surveillance, and goes out of control (becomes a tumor). The inheritance of retinoblastoma is via the passing along of the one disabled copy of the code to a child. Many adult cancers, such as breast cancer, and colon cancer, are inherited by a similar "two hit" mechanism. Oncogenes can generally *not* be inherited, because the production of a toxic protein so early in life would almost certainly not be compatible with the baby even being born.

DNA Structure

There is a third type of cancer gene, namely those involved in repair of damage to genes; this group seems more important for human colon cancers, and not as much pediatric tumors. However, one can easily imagine that the gradual loss of the ability of a cell to repair damage to the code would result in the failure to correct changes to the code of oncogenes and tumor suppressors, which is precisely what happens.

In all tumors, it is often a series of genetic changes of *both* to create oncogenes, and changes to remove tumor suppressor genes. Precisely which events occur to which genes determines the type and aggressiveness of the tumor. Scientists and clinicians realize that only a small fraction of the changes are known for any tumor, although some specific changes clearly have a dramatic effect (for example, the new oncogene created with the Philadelphia chromosome translocation). It is the complexity of cancer which makes new high-tech approaches such as gene microchips so promising. These developments, and the specific gene changes associated with specific pediatric cancers, will be described in the next issues of the newsletter.

Dr. Hoffman has had a long-term interest in genetics and it's implications for health and disease. As a post-doctoral fellow, he participated in the identification of the first 'positionally cloned' human gene and the identification of its protein product. He is currently Director of the Research Center for Genetic Medicine at the Children's National Medical Center in Washington DC, Professor of Pediatrics at George Washington University (and is married to wife Ruth.)

Candlelighters International Conference:

Childhood Cancer and the Family: Together in 2000
A Childhood Canada Conference
August 18 - 20, 2000
Toronto, Ontario

The 4th international Candlelighters Parent conference is co-hosted by the Parent Groups of Ontario and The Childhood Cancer Foundation Candlelighters Canada.

Dr. Bernie Seigel will give the opening keynote address.

Other well known speakers include: Nancy Keene, well known childhood cancer author, Sr. Frances Dominica, an international expert on children's palliative care and hospice care, Dr. Lauren Woodhouse, a laughter therapist and Dr. Mark Greenberg who will speak on long term effects. Special events are planned for the children who will be spending their days in recreational programmes designed by the staff of Camp Trillium.

Plan to include this important event in this summer's activities. Hope to see you there!

Further Information can be obtained by contacting:
Candlelighters Canada
55 Eglinton Avenue East, Suite 401, Toronto, Ontario M4P 1G8,
Ph:416 489-6440; Fax 416 489-9812
Email: staff@candlelighters.ca Website: http://www.candlelighters.ca

Resources:

Websites:
Candlelighters Info:
http://www.candlelighters.org

General pediatric oncology Info:
http://www.acor.org/ped-onc/

Bone Marrow Transplant Info:
http://www.bmtnews.org

The Brain Tumor Society Info:
http://www.tbts.org.

The American Society for Clinical Laboratory Science: will answer questions about laboratory values.
http://www.ascls.org/labtesting/index.html

Kids Cancer Camp Info:
http://www.acor.org/ped-onc/cfissues/camps.html
http://www.COCA-intl.org

Projectlinus (Free blankets for critically ill children):
http://www.citiusa.com/projectlinus.html

STARBRIGHT Explorer Series™ Interactive Health Care Programs

The following videos are available free upon request by a young person with a serious illness.
Visit: www.starbright.org ; Call: 310-442-1560
Or write: Starbright Foundation, 1990 South Bundy Dr., Suite 100
Los Angeles, CA 90025

The Starbright Foundation is a non-profit organization chaired by Steven Spielberg and Gen. Norman Schwarzkopf. In this series of health care programs, children and their families learn about medical procedures and conditions in a fun and engaging manner. The programs are designed to empower children with knowledge and stimulate dialogue between children, families, and healthcare professionals. The following programs are featured on STARBRIGHT World and are now available on CD-ROM. Additional titles include: Uncovering the Mysteries of Bone Marrow; and Spinal Tap: Discovering the Secrets of Spinal Fluid.

Blood Tests: Exploring Our Incredible Blood
This program sends children on an educational journey through the blood, introducing them to the fascinating facts that can be learned about the body from a single blood test. Children view red and white blood cells, bone marrow and platelets under a microscope, discover how the balance of chemicals affects the blood and body, test their knowledge and look up additional information in a glossary. *Ages 10-15*

Spotlight on IVs
Children often have many questions about how an IV works and feels. Now, with the help of Nurse Ima Helpa, children can get the answers to their questions about IVs. Ima provides easy-to-understand answers for children who have never had an IV, as well as veterans of the procedure. In addition to answering the questions "What is an IV?", "Why do I need an IV?" and "How does an IV work?", Ima offers relaxation techniques for making the procedure a little less scary. *Designed for ages 6-10.*

...continued from page 3

- cyclophosphamide (Cytoxan), ifosfamide. High doses of these drugs can cause malfunction of bone marrow causing abnormal cells (myelodysplastic syndrome) or acute myelocytic leukemia (AML).
- Epipodophyllotoxins—VP-16 (etoposide), VM-26 (teniposide). These drugs cause acute myelocytic leukemia (AML) in a small number of survivors.
- Platinum analogs—cisplatin, carboplatinum. The research is not clear concerning second cancers after treatment with these drugs. Most AML or myelodysplastic syndromes occur when the platinum drug is given in conjunction with alkylating agents or epipodophyllotoxins.

Secondary leukemias that occur in those treated with alkylating agents and/or epipodophyllotoxins are usually seen in the first ten years after treatment. Solid tumors tend to occur many years or decades after treatment ends.

Risks after treatment

After reading the above, you may be wondering what your actual risk of developing a second cancer is. It isn't possible to address your particular case because your risk depends on your age at treatment, the amount and location of radiation, the total doses of chemotherapy drugs, and perhaps your genetic predisposition to cancer. A physician who knows your medical history and is well informed about late effects can best help you estimate risk in your individual case.

Many of the treatment-related second cancers discussed earlier are attributed to treatments that are not considered standard of care today. Many current clinical trials are focusing on maintaining cure rates but using less toxic treatments. Thus, in the future, it is hoped that cures will continue to increase, while treatment-related second cancers decrease. All survivors, however, need life-long surveillance for second cancers to provide either reassurance that you are in the large majority of survivors who have no second cancer, or to diagnose any problem early.

Prevention

Once you know what your risk might be, what can you do? Practical ways to deal with this information are to do everything you can to prevent a secondary cancer and get regular check-ups. While you cannot alter a genetic predisposition or damage done from radiation, you can modify risk factors by making healthy choices. Some of these are:

- Don't smoke
- Exercise regularly (at least three times a week)
- Maintain a healthy body weight
- Eat four to six fruits and vegetables a day
- Learn how to do breast or testicular self-exams, and do them every month
- Get regular check-ups
- Drink alcohol only in moderation
- Don't take illegal drugs or recreational inhalants
- Avoid exposure to the sun and use sunscreen, particularly on irradiated skin

Taking control of your risk for second cancers includes regular check ups by a physician who knows your history and risks as well as making healthy lifestyle choices.

Nancy Keene is the author of Childhood Leukemia; Childhood Cancer: A Parent's Guide to Solid Tumor Cancers; (with co-author Honna Janes-Hodder); Your Child in the Hospital, and Working with your Doctor. She is currently writing a book for survivors due for release in May. Nancy is the mother of an 11 year old daughter Kathyrn who is a survivor of high risk ALL and 9 year old daughter Alison.

Kevin Oeffinger M.D. is director of a multidisciplinary program for young adult survivors of childhood cancer at UT Southwestern at Dallas. He enjoys backpacking, running and hiking with his wife Patty, son Daniel (16) and daughter Ashley.

Letters From Our Readers:

To the Candlelighters,
Hello. My name is Jessica. I am 14 years old and have a rare bone cancer called PNET. Seven out of one million children get it a year. I guess that I was just one of the lucky ones. I have gone through intense chemotherapy and am disabled from it. I have to walk with braces on my ankles because I had neuropathy and got a foot-drop from it. I got very ill at one point and had to be put on a ventilator. I am recovered now but still have my stories to share and still a little more chemo to do. I wrote to tell you that I think it is great what you're doing. I want you to know that children that are ill will probably be the strongest and bravest people you'll ever meet. I met my best friend in the hospital. She has leukemia and is the most wonderful person I have ever known. So from all the ill children, Thank you!

Heidi Goldstein: Heidi is an **adult sibling** of survivors of childhood cancer and is interested in starting a local support group or on-line message board for adult siblings which she would be willing to set up if an interest is expressed. Heidi can be contacted at: heidig@heidig.com or by phone at 703-299-8850.

Joshua Grossman MD: Joshua is an **adult survivor of childhood cancer** who would like to connect with other similar young adults. Josh is currently clinical assistant professor of Psychiatry and internal medicine in Tennessee. To contact Josh, he can be emailed at: jo shmick@usit.net or write to him at: 1005 Melrose, Johnson City TN 37601.

TAYLOR AND THE HAYLOFT

by Taylor Waite, Age 8, Butler Missouri, January 11, 2000

It was a cool fall Sunday afternoon in November, my family and I decided to go to my Grandma's house for the day. My cousin Brandi and her husband Big Bryan, live very close to my Grandma's house, so we went up to visit them. At my cousins house we have a playhouse. My sister Brianne, and I wanted our Mom to see the hayloft. My Mom is really afraid of heights, but she said she would go up there and see our playhouse if we really wanted her to. We climbed up the steep ladder which was about 8 feet to the top of the loft. My Mom was really happy with all the work we had done to our playhouse. We went back into Brandi's house to visit for a while. I realized that I had left my gloves in the hayloft, so I decided to go back up and get them. I didn't tell anyone that I was going back up there to get my gloves. I climbed back up the 8 foot ladder and was standing with my back to the opening in the floor. I saw my gloves in my hat, but I accidentally stepped back and fell through the opening in the floor. I wasn't really sure what had just happened , but I jumped up and tried to run to the house, but I fell to the ground a couple of times trying to get there. Brianne met me at the door and started screaming and crying for Mom. My Mom grabbed me up and said we are going to the hospital. My Mom put a towel against my head, I could see blood all over the towel and my jacket. My Mom told my cousin Brandi to go find my Dad and Big Bryan back in the field where they were cutting wood.

Brianne called my Grandma Judy on the CB radio, and she was there to drive us to the hospital. All I remember about the ride to the hospital was that Grandma was driving really fast, and I was getting really tired. My Mom kept trying to wake me up, but I just wanted to take a nap. Dr. Long met us at the hospital. He said I had a really deep cut on my head and a bad concussion. Dr. Long put 17 stitches in my head. Dr. Long said the cut was so bad that he could see a big part of my skull. After Doc put the stitches in, they took me to have a bunch of pictures taken of my head.

I'm not really sure what happened after that, but my Mom and Dad were really upset. Dr. Long decided that I should stay in the hospital that night because they were going to send me to see another Dr. the next day. It was kind of fun spending the night in the hospital because all of my family was there. My big brother Rance came to see me, my Aunt Pam came down from Belton, my cousin Lindsay came over from Warrensburgh and my Nanny and Poppa were there too. I was getting all kinds of attention.

The next day we went to Children's Mercy in Kansas City, MO. While we were there, they did an MRI, which takes pictures of my head. Mom and Dad met with a Dr. after my MRI. He told my Mom and Dad that I had a brain tumor, and that it was in a very hard place to get to. Mom and Dad were very upset and Mom cried a lot. This Dr. told Mom and Dad that if I had to have surgery, that he would not be able to do it because the tumor would be too dangerous to try and get to. He told Mom and Dad about a Dr. in Boston that was suppose to be very good, his name is Dr. Scott.

In December my Mom, my Aunt Pam, my cousin Lindsay and I flew to Boston to meet with Dr. Scott. When I first met Dr. Scott I thought he looked like a clown because he was very short and wore this little bow tie, but he was very nice and I liked him a lot. He checked me over really well and made me watch his finger and he checked my reflexes with this little hammer. Dr. Scott told my Mom and Aunt Pam that we shouldn't do anything about the tumor right now, we should just wait and watch it and see what happens.

In February it was time for me to have another MRI done. We found out that the cyst around my brain tumor had increased a lot. The Dr's told us that we should get to Boston right away and have surgery done. If I didn't, I could have serious problems.

In March, my Mom made plans for us to fly back to Boston for me to have surgery. Before we left for Boston, my Mom's good friends Kelly and Kathy planned this great surprise party for me at my school. I had a great time, we played games, danced, and the High School Cheerleaders even came and did cheers just for me. The Butler newspaper was there to take my picture with the cheerleaders and put it on the front page of the paper. This was the best party I have ever had.

When we got to Boston, the nurses were getting me ready to go into surgery. I was a little bit nervous about going into surgery, but I made friends with all the nurses. I was telling them jokes and made them laugh. I don't remember anything about the surgery, but when I woke up, I didn't feel very good. My Mom and Dad, my Aunt Pam and my Nanny and Poppa was there. They moved me to my own room and I stayed there for 7 days. The Dr's had me on steroids, which I called 'the juice'. This kept me awake for over 80 hours. My Mom and Dad were really tired, but I just kept on going and going and going…I talked a lot and told lots of jokes to the nurses. The bad thing was that Dr. Scott was only able to get 20% of my tumor, so I had to see lots of other Dr.'s so they could decide what I needed to do next.

Before we left Boston, my Mom and I and Aunt Pam were able to do some sight seeing. We went up in the John Hancock Building which was 60 stories high. We were able to see Fenway Park with the big green wall, and we also went to the aquarium at the ocean. We had a lot of fun before we flew home.

I am now taking chemotherapy. I had a port put into my chest so they could give me my medicine. I do not like taking chemotherapy because I have to miss school, and I don't like that. Sometimes it makes me feel sick, and I don't' like that either. I know that I need to take the chemotherapy because the Dr.'s hope that it will make my tumor shrink and that is what I want too. I'm not sure how long I will have to take chemotherapy, but it is just something that I have to do.

My Mom says that I am really brave and strong because most kids wouldn't have been able to make it to the house after falling 8 foot and cutting open their head. My Mom also says that I make her strong because I have to go through so much and I just do it. I also think that I have an angel that watches over me and protects me all the time. They don't call me 'BIG DOG' for nothing!!!

Candlelighters would like to thank Taylor for his inspiring story.

Wishing you all the best Taylor!

Thanks!!!

To Mike O'Brien for all his efforts as President; to board member Bob Wilbur for his ready responses to dozens of questions; for all those who helped with the recent office move (Mike O'Brien and his family; Bob Wilbur; Christa Cohan; Steve Howland; Bill Spencer; sRuth and Eric Hoffman and children); to Steve Payne and Roy Kaufman for the many hours they have spent on the Candlelighters' website and listserve; to Mark Chesler for the new publication and meeting all deadlines; Ken Phillips for his work as treasurer; Nancy Keene and Kevin Oeffinger MD for continuing to donate their time to write for the 'Quarterly'; to all contributors to the newsletter including Kenon Neal and the Kids Cancer Network's Fun Page; and a warm farewell to Doug Gold, who has just left the Candlelighters office after a year of valuable transitional help. Good luck in your new directions!

… Because Kids Can't Fight Cancer Alone!

We're on the Web
www.candlelighter.org

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

Please send correspondence to:
Candlelighters Childhood Cancer Foundation
3910 Warner Street
Kensington, MD 20895

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