



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

Candlelighters™

Childhood Cancer Foundation

Fall/Winter 2007

The National Journal of Candlelighters

'Naomi's Hope for a Cure' Gala



Naomi was treated for an acute form of leukemia (acute myelogenous leukemia) in 1987 when she was 7 years old. This November she will celebrate the 20th anniversary of the bone marrow transplant that saved her life. The aggressive treatment that she received as a young girl resulted in a second cancer battle in November 2004.

While fighting cancer twice, Naomi treasured all of the letters, notes, and gifts of encouragement that she received. All were saved in numerous types of 'Hope Chests,' and all symbolized the 'hope' that she needed to fight the cancer battles.

'Naomi's Hope for a Cure' (www.Hope4aCure.net) celebrates



George H. W. and Barbara Bush signing a Hope Chest to be auctioned at the Gala.

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Naomi's life and the lives of all children and adolescents who fight this disease through a gala dinner, live auction and silent auction to be held in Washington DC. Fifteen wooden 'Hope Chests,' all hand painted by famous artists or signed by celebrities will be auctioned off at the event.

Artists who have painted a 'Hope Chest' include America's prodigy Alexandra Nechita (www.nechita.info), world famous Canadian painter Robert Bateman (www.robertbateman.ca), his son and successful painter Alan Bate-

man (www.alanbateman.ca), California Senator Dianne Feinstein, Extreme artist and Entertainer of the year Jean Francois (www.extremearth.com), Hawaiian artist Nancy Hoke (www.nancyhoke.com), Canadian Holly Carr (www.hollycarr.ca), well known Oklahoma artist Denise Duong (www.deniseduongart.blogspot.com/), children's author and artist Trevor Romain (www.trevorromain.com), Candlelighters' own board member Ken Phillips, and others.

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Childhood Cancer Awareness Tree Lighting 2007

by Ruth Hoffman MPH

Light Up the Holidays with Hope' has become our Nation's largest childhood cancer awareness event. The 8th annual holiday event will be held on Saturday December 8th 2007, at the Old Post Office Pavilion, 1100 Pennsylvania Ave N.W., Washington DC.

Each year during the December holiday season, a 23 foot tree is placed in the lobby of a building on Capitol Hill, Washington DC. The tree is solely decorated with thousands of gold ribbons (the symbol for childhood cancer), with each ribbon bearing the name of a child who has, or has had cancer. The tree glitters strong in our nation's capitol for all to see. Thousands each year are touched as they are reminded of our nation's youngest cancer patients. I encourage all Candlelighters' families to participate in this unique event and support childhood cancer awareness by adding your cancer child's name to the National Tree. Ribbons are \$5.00 each and can be purchased on-line by clicking on the link at: www.candlelighters.org. Ribbons can also be purchased using the form in this newsletter and mailing a \$5.00 check per ribbon to: Candlelighters, P.O. Box 498, Kensington MD 20895-0498.

Each year, a lighting ceremony is held to light the tree, honor our cancer children, and enjoy some fun activities with our families and friends. In keeping with last year's event, time will be given to all families attending this year's event to come to the microphone during the program to pay tribute to their child who was diagnosed with cancer.

I am thrilled to inform you that this year's guest speaker and musician is Matthew Zachary. Matthew Zachary was a 21 year old college student and concert pianist when diagnosed with a form of pediatric brain cancer. Told he would never perform again, Matthew chose to get busy living. Twelve years,

four albums and hundreds of concerts later, Matthew is now an emerging leader in adolescent and young adult cancer advocacy as the founder of the innovative I'm Too Young For This! Cancer Foundation a global support community for young adults affected by cancer, and ranked by TIME Magazine as a Top 50 Website for 2007. His mission and vision are to end the isolation faced by so many and to use music and the arts to help young survivors create, connect and unite. For more information on Matthew and his commitment towards more and better treatments for pediatric and young adult cancers, please visit <http://ImTooYoungForThis.org>.

'Light up the Holidays with Hope' is also a fun family time. This year's entertainer will feature Jason the Juggler. For the last decade Jason Huneke has been entertaining at corporate events, fairs, and festivals. Known to captivate all age groups using his unique blend of comedy and coordination including unicycling, balancing, and juggling, Jason keeps the crowd laughing along with him.

This year's event will also include fair-type fun activities for your children, toys and gifts, as well as lots and lots of food!

Please support this important event through the purchase of a gold ribbon in honor or memory of your cancer child. These will be placed on the National Childhood Cancer Awareness Tree. We hope that many of you will be able to attend the tree lighting and post-lighting events.

Hope to see many of you there!



Above: Jason
Huneke
Right:
Matthew
Zachary



Gold ribbons can be purchased on-line at the National website: www.candlelighters.org
(Child tributes can be added via the web.)

Gold ribbons can also be purchased for \$5.00 by mailing your check & form below to:
Candlelighters National Office
P.O. Box 498, Kensington MD 20895-0498

Child's Name: _____

Age: _____ (circle months or years)

State: _____

In Honor of: _____

In Memory of: _____

Check if your family will be attending the tree lighting ceremony

_____ Number of children attending

_____ Number of adults attending

Phone No. () _____

Email: _____

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

Name: _____

Address: _____

Chemotherapy vs. Transplant as Treatment for Relapsed ALL

Acute lymphoblastic leukemia (ALL) is the most common childhood cancer. First-remission treatment for ALL is generally standardized, and 80% of children can be expected to achieve a five year event free survival. However, children who do relapse can have treatment options to choose from. Some relapses of ALL are clear cut as how to treat, while some lie in a grey area between transplant and chemotherapy. For instance, combined late relapses fall into this grey zone.

What is a combined relapse?

A combined relapse occurs in both the bone marrow (BM) and extramedullary (EM) fluid. For both Europe and North America, a combined relapse is considered to be BETTER than an isolated marrow relapse, with survival rates supporting this point of view.

What is time to relapse?

While there are numerous factors that impact the probability of achieving a second remission after a relapse, the time from first remission (or if you prefer, from initial diagnosis) to relapse is one important factor. Children who relapse while on their initial treatment have been shown to have a lesser probability of achieving a second remission and subsequent five year survival. These patients have also been shown to have shorter second remissions in comparison to patients who relapse after their initial treatment was complete. Additionally, the length of time that a patient was off treatment prior to the relapse also has been shown to correlate with the probability of achieving a second remission. Studies have shown that those children who relapsed more than 6 months after the completion of their initial treatment had a better five year outcome as compared to those children who relapsed earlier. The European clinical trial study group known as the I-BFM or International Berlin-Frankfurt-Munster group classifies a combined relapse that occurs after 6 months off therapy (OT) as a late

relapse. In contrast, North America's clinical trial group known as the Children's Oncology Group or COG defines a combined relapse after 1 year OT as a late relapse.

What are the treatment options?

A stem cell transplant is the infusion of non-cancerous hemopoietic stem cells into the patient to replace their cancerous marrow. An allogeneic transplant occurs when the healthy marrow is donated by an HLA matched individual such as a sibling or matched non-related donor (MUD), after the patient has been treated with high dose chemotherapy and possibly total body radiation. An autologous transplant occurs when the patient's own marrow has been harvested and treated and then re-infused back into the patient after being given high dose chemotherapy and possibly total body radiation. A cord blood transplant uses fetal stem cells that were harvested from the umbilical cord at the time of birth.

Through the use of a high dose conditioning therapy, the bone marrow and associated leukemia cells are destroyed. The donor cells are given to rescue the patient from bone marrow failure. Without donor cells, the high dosage of chemotherapy and radiation used in conditioning for the transplant would literally kill the patient. In addition, the donor cells are also used in the attempt to stimulate a graft vs. leukemia effect so that the donor cells attack any remaining few leukemia cells in the patient, having recognizing them as foreign invaders. In contrast, treatment for relapsed ALL using chemotherapy alone involves the use of chemotherapy at dosage levels that are not in themselves a lethal dose, requiring donor stem cell rescue.

Chemotherapy alone vs. transplant?

In making a decision between transplant or chemotherapy alone, these are some factors to consider.

- Transplant = a higher cure rate & possibly a shorter overall treatment time. However, treatment with a stem cell transplant will incur more toxicity, more treatment-related mortality, increased possibility of long term effects such as chronic graft vs. host disease (GVHD) which may result in the patient being in-hospital for a long period of time. Potential long term late effects associated with the higher intensity treatment can include sterility, growth deficits, late neuro-cognitive deficits, secondary cancers, long term immunosuppression, cataracts, and other chronic health conditions.
- Chemotherapy alone = lower cure rate and a two to three year treatment time frame. The treatment is comparatively less toxic, with less treatment-related mortality, and overall less likelihood for chronic late effects. The downside to be considered is the decreased probability of achieving a third remission if the child relapses a second time, with accumulated toxicities involved as a result of 6 years of chemotherapy treatment plus a bone marrow transplant.

Finally, another factor to consider when discussing possible transplant for the child with relapsed ALL is how different types of transplants affect the cure rate.

When you are comparing cure rates between chemo vs. transplant, make sure that you know which type of transplant it is:

- Fully matched antigen sibling transplant
- One (or two) antigen mismatched sibling transplant
- Fully matched antigen unrelated donor transplant
- One antigen mismatched unrelated donor transplant

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A Message from Executive Director Ruth Hoffman MPH

Dear Families,
Over the past several months, Candlelighters has taken a lead advocacy role on an issue of great importance to children with cancer. Congress is currently debating two competing versions of legislation that will allow the FDA to approve generic 'copies' of the targeted therapies (called 'biologics') that have proven so effective in treating many adult cancers.

As you may know, children with cancer have not yet been the beneficiaries of these breakthrough biotech treatments. That's why I've been encouraging Candlelighters families to join me in support of the legislation that will give children with cancer the best chance of reaping the therapeutic benefits of *tomorrow's* biologic drugs.

In May, I was invited to testify on this issue before a Congressional Health

Subcommittee. Over the summer our members have been signing a petition via Candlelighters' website to encourage Congressional support for this issue, when it comes to a vote this fall. Please note that on the facing page of this newsletter there's a template letter to Congress that I hope you'll sign and mail back to me, in support of this important issue to our nation's children with cancer.

But first let me explain why this issue is so important to our kids' future.

Biologic products, which are complex human proteins that have been adapted for therapeutic use, are among the most promising and effective medicines for the treatment of serious and life-threatening diseases, including cancer. To date, there are numerous biologics being used to successfully treat adult cancers, such as Herceptin and Trastuzumab (treats breast cancer)

and BCG or Bacillus Calmette-Guérin (treats bladder cancer). Unlike conventional cancer treatments that target all dividing cells, biologics target the genetic change in the cell that leads to the cancer growth. Currently there are no biologic products that have been developed by biotech companies and approved by the FDA specifically for pediatric cancers. These products are very expensive and time consuming to produce. It is estimated that a biotech company will spend 15 years and \$1.2 billion to develop one new biologic and bring it to market.

As we know only too well, children with cancer need treatment breakthroughs! They need new molecular-based therapies that will 'kill the cancer, not the kid.' Current toxic therapies offer little hope for cure for many childhood cancers, and research has shown that 2/3rds of

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Suicidal Thoughts and Attempts in Adult Survivors of Childhood Cancer

by Christopher Recklitis, Ph.D., MPH, Monica A. Rothwell, Linda Zame PhD

Background
While most studies show the majority of cancer survivors are emotionally well-adjusted, several studies indicate that survivors may be at risk for emotional problems including suicidal thoughts. We examined the prevalence of suicidal thoughts and attempts in a sample of adult survivors of childhood cancer. Our main goal was to identify risk factors for suicidal symptoms.

Why study suicidal thoughts and not depression?
Suicidal thought is closely related to depression, but people who have thoughts of suicide may not be depressed. This

may be especially true for people with serious medical conditions where pain or physical limitations may make some people feel life may not be worth living. Also, suicidal thoughts and prior attempt are significant risk factors for later suicide, and indicators of serious emotional suffering.

Who participated and what did they report?
Participants were 226 adult survivors of childhood cancer seen in a survivor clinic. There were 100 men and 126 women, ages 18-64 years old. Participants completed rating scales including two questions about current thoughts

of suicide (in the past week), and one question about any previous suicide attempts. Twenty-nine of the 226 survivors (about 13%) reported suicidal symptoms. Although no national statistics on suicidal thoughts and attempts are readily available, several studies indicate that rates of suicidal symptoms are considerably lower in the general population with rates between 2% and 4%. Compared with these estimates from national studies, our finding 13% of survivors experiencing current suicidal thoughts appears to be quite high and very concerning.

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Message from the Board — October 2007

Janine Lynne, Co-President CCCF

This is the time of year we look at what we have accomplished over the past year and what lies ahead. The world of childhood and adolescent cancer has many needs, and as a leading patient advocacy group we are acutely aware of them all. To move to the next level of support and advocacy, our board has focused this year on strengthening our organization. We have also added several new affiliate groups in much needed areas, and we are working to strengthen our partnership with all our affiliates. To address the issues of survivors and the stall on new research, we expanded our mission to focus on less toxic treatments for our children/adolescents today and tomorrow. We are actively collaborating with other grassroots and patient advocacy groups to strengthen our numbers and our influence. We will also be launching a newly designed website soon to make the information we have

easier to find. We know how important current, accurate information is to families and survivors; we receive over 3 million hits a year on our website.

Our coming year is filled with opportunities. We have many goals. We need to expand awareness, we need more products and written material to fill the void of information for families, and we want to build more affiliate organizations in more communities until we reach every family that has a child diagnosed with cancer. We will also be increasing our fundraising goals to meet these needs. Two ways that we know we are reaching those who need us is by our newsletter which goes out to over 26,000 people and by the donations that come in from family and friends. While we love the big donations, it is the \$5-\$10 donations from all over the country that also mean so much to us. Those are the donations

that tell us while we still have a lot of work to do, what we do today matters. I hope everyone will remember that this December when we send out our annual letter drive, if you receive this newsletter and want to let us know you appreciate what we do, please consider a donation, however large or small.

One of the benefits of serving on the board of directors is the knowledge that Candlelighters is a part of something that really matters. When you step back and look at who we are – the dedicated affiliates who work with families in the communities every day; the families, the children and the adolescents themselves; the long term survivors and their spouses; the professionals who are wholly committed to caring for our children – it is an honor to be a part of such an organization.



Health-Related Outcomes for Hodgkin Disease Survivors by Dr. Debra Friedman COG ALTE04N1

This is an important study for survivors of Hodgkin disease who were treated from 1987 to the present. It is being conducted in a number of institutions in the Children's Oncology Group (COG). We are looking for study participants and we invite you to learn more about this study.

Why are we doing this study?

Survival from pediatric Hodgkin disease now exceeds 85%, resulting in a growing cohort of survivors who may be at risk for late effects. With changes in therapy over time, the prevalence, incidence, and spectrum of such effects is likely to change. While there are data on late effects for patients treated in the 1960's through the early 1980's, there is little collected information regarding

similar outcomes for patients treated in the more contemporary era from 1987 to the present. During this period, we designed studies in part to reduce long-term adverse effects. Examples of changes in therapy included a reduction in the use of alkylating agents, anthracyclines and radiotherapy, specifically to decrease late effects in areas of cardiopulmonary, endocrine, reproductive, and psychological health and to decrease the incidence of secondary malignant neoplasms.

Current late effects screening recommendations are largely based on studies of Hodgkin disease survivors treated in the earlier era of chemotherapy and radiotherapy, and may not be applicable to more contemporarily

treated patients. Survivors treated with less intensive therapy may need different screening, if indeed the risk profile has changed. Similarly, the spectrum and incidence of late effects experienced by these patients can inform us with respect to the design of future risk-adapted therapeutic trials.

What are the specific aims of the study?

Aim 1: Characterize the prevalence and spectrum of selected adverse physiologic and psychosocial outcomes, and report the cumulative incidence at 5, 10 and 15 years from diagnosis.

Aim 2: Compare the prevalence, cumulative incidence and spectrum of these

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Affiliate Corner

by Mary Anne Ruddis

Executive Director, Inland Northwest Candlelighters

The Inland Northwest Candlelighters, located in the state of Washington was formed in 1977. We have provided continuous services in this region since our inception thanks to many dedicated volunteers. We serve families who travel from throughout Eastern Washington, Northern Idaho, and Western Montana to receive treatment here in Spokane at Sacred Heart Children's Hospital.

Of our many services, programs, and events, our Annual Candlelight Vigil, held in September to coincide with Childhood Cancer Awareness Month, is the most poignant.

During Childhood Cancer Awareness Month we bring attention to the fact that childhood cancer is still the number one disease killer of children. We also bring awareness to the many issues that families face after hearing the words, "your child has cancer."

At our tenth annual Candlelight Vigil on September 30, 2007, we presented our just completed "Candlelighters Remembers" memory scroll. Painstakingly and lovingly hand-drawn, the names of our children are forever immortalized. We hope to never add another name, but the unfortunate truth is that we will. Children are still dying from cancer. We are continually reminded that childhood cancer is considered rare, but it seems anything but rare when you walk onto a pediatric oncology floor or if it is your child who has just been diagnosed.

Our vigil is a time to recognize the struggles of our children and their families and reinforce that kids can't fight cancer alone. It takes all of us. Our children still fight childhood cancer longer after the official treatments end. And our families are left living in a world of uncertainty.

Our vigil is also the place where we publicly remember those children who



Candle Vigil

now live on earth only through us. We know the impact that their short lives have made in the world. We live in the wake that the ripple of their lives created.

We all create ripples and leave wakes. Every action we take creates unforeseen events – sometimes for good, sometimes not so good. I just heard a story that I have heard before in different variations. It is a story about ignorance and the need to educate the public during childhood cancer awareness month and throughout the year.

A man approached a young cancer patient and her mother as they stood in line at a store and asked if her head had been run over by a lawnmower. I am sure he thought that she had taken scissors to her hair as kids sometimes

do. And I choose to believe he thought he was being clever and funny and not cruel. But he made a serious miscalculation. He was neither clever nor funny. He was hurtful.

He faced this mom square in the face with the fact that her beautiful daughter did not look "normal" anymore. It wasn't something she had forgotten, but it pales in comparison on the loss scale when you are dealing with your child's life. It was a powerful reminder of another layer of loss that childhood cancer brings. Kids going through cancer treatments look different. As parents, we feel guilty for grieving that loss given the enormity of what we are facing. But our children become the object of strangers' ignorant remarks. And that hurts us.

This unknown man could not foresee that his comment would reach into this newsletter. Just as we cannot foresee that our comments, our kindnesses, and even our mistakes will float into time on the ripples that we create. Being mindful of our impact in the world can create ripples of goodness and support. And if we are watchful, we may see the effects.

Candlelighters draws its strength from numbers. Together we can make a tidal wave that will have a positive impact on a very negative situation. We are proud to stand together with all of the dedicated Candlelighter affiliates across the country as we lift the burdens of childhood cancer patients and their families, while at the same time, no longer waiting for a cure, but actively working towards that end.

Naomi's Hope for a Cure Gala Event *continued*

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Celebrities who have signed a 'Hope Chest' include George H.W. and Barbara Bush (pictured), Tour de France 7 time winner Lance Armstrong, cancer climber Sean Swarner, and BMX extreme athlete Mat Hoffman.

Funds raised from the event will be allocated towards developing new types of 'smart' drugs to treat children and adolescents with cancer. Scientifically, we have reached an era where scientists can use cutting edge techniques to determine the genetic 'fingerprint' of tumors. With that information, it is possible that new types of drugs can be developed that target JUST those genetic changes that have led to the cancer. Today, our nation's children with cancer continue to be treated with toxic drugs that were developed 20-30 years ago. Children with cancer need these new types of drugs to give them hope for a future and a complete cure.

There are many ways to participate.

- Make an online donation at www.Hope4aCure.net in honor of someone you love. (All names will

- be added to the gala catalogue).
- Become a corporate sponsor
- Attend the gala. Tickets are available online at the gala website.
- Donate an item for the silent auction (all items are tax deductible)
- Spread the word to your friends, family, colleagues and art lovers about this incredible opportunity to purchase an original piece of art painted by famous people or signed by our nation's celebrities.



Continue to check out the gala website for the pictures of the 15 Hope Chests painted by renowned artists that will be auctioned off!!



George H. W. Bush, Naomi Bartley, Barbara Bush, artist Denise Duong and Ruth Hoffman standing in front of the signed Hope Chest to be auctioned at the Gala, November 16.



Combined Federal Campaign — NEW NUMBER is 11774

Each year federal employees are given the opportunity to donate to an organization through deductions from their paycheck. We ask those of you who are able, to please consider making Candlelighters your charity of choice for your CFC donations.

and family foundation grants. Financial support through your CFC donation will make a huge difference to helping our organization continue to provide these essential childhood cancer services.

Candlelighters' receives no government funding. All programs, books, services, representation on cancer committees are provided without charge, and are funded through individual donations

Please add our number 11774 to your CFC donation today, and help us raise \$100,000!



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Health-Related Outcomes for Hodgkin Disease Survivors *continued*

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targeted adverse outcomes, using self-report, with a cohort of patients treated from 1970-1986.

Aim 3: Compare self-reported health-related outcomes with those detected by clinical evaluation or medical record review.

Who is eligible?

Hodgkin disease survivors, treated between 1987 and 2002 with chemotherapy and/or low-dose radiation (< 30 Gy or 3000 cGy) therapy, who were less than 22 years of age at the time of treatment are eligible for this study. You can be any age currently to participate.

Where is this study taking place?

The study is taking place at the following institutions. Patients need to have received their treatment at one of these institutions or be seen in the long-term follow-up program for this evaluation.

- Children's Hospital of Seattle
- Children's Hospital of Philadelphia
- Rhode Island Hospital, Brown University
- Yale University
- University of Texas Southwestern
- St Jude Children's Research Hospital
- Texas Children's Hospital
- University of Rochester
- Memorial Sloan Kettering
- Hackensack Medical Center
- University of Chicago
- Stanford University
- Columbia University
- Cincinnati Children's Hospital

What will this study involve?

A. Medical Record abstraction

All patients will have been enrolled on, or treated with identical therapy as cooperative group or consortium clinical trials. The institutional principal investigator will be responsible for providing treatment data (cumulative chemotherapy doses and radiation treatment fields and volumes) to correlate with health outcomes. The source of the treatment information (individual chart

abstraction, clinical trials database) will be recorded.

B. Self report data

All subjects will complete the following self-report questionnaires, which can be completed at home, and brought to the institution on the day of the clinical evaluation, or mailed in.

1. Childhood Cancer Survivor Study Questionnaire
2. Post-traumatic stress Questionnaire
3. Fatigue Questionnaire
4. QOL (Quality of Life) Questionnaire

C. Clinical evaluation

All subjects will receive a comprehensive risk-adapted clinical evaluation using the COG Late Effects Screening Guidelines as appropriate for Hodgkin disease and specific therapeutic exposures. For each guideline, the prevalence of both symptomatic and asymptomatic physiologic and psychologic health outcomes will be determined. Data on patient, physician and third party payer refusal to perform recommended screening will be collected for each guideline. Since medical follow-up and the tests being done are now considered standard of care, you will be charged for this evaluation. Generally insurance covers these long-term fol-

low-up visits, but you will want to check with the institution.

The clinical evaluation will include:

1. Complete health history and review of systems
2. Review of documented medical problems from the medical record
3. Complete physical examination
4. Laboratory and diagnostic studies as determined by the COG Late Effects guidelines, by specific chemotherapy and radiotherapy exposure.
5. Receipt of a comprehensive treatment summary for you and your primary health care provider.

What do you need to do if you are interested in participating in the study?

If you were treated at one of the participating institutions or are currently being followed there, contact their survivorship long-term follow-up clinic and let them know that you want to participate.

If you were not treated at any of these institutions but are still interested, or want to know more about the study, contact the principal investigator Dr. Debra Friedman at: dfriedma@fhcrc.org; 206-667-5935.

We look forward to having you join this study!!!

Chemotherapy vs. Transplant *continued*

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- Fully matched cord blood transplant
- One, two or three antigen mismatched cord blood transplant

All have different outcomes. Specifically:

1. Best outcome = fully matched antigens (6/6 HLA sibling transplant)
2. Outcome about 5% - 15% lower than (1) = one antigen mismatched sibling transplant and fully matched unrelated donor transplant and up to two antigen mismatch cord blood transplant
3. Outcome about 5% - 15% lower than (2) = two antigen mismatched sibling transplant and one antigen mismatch unrelated donor transplant
4. Unknown outcome = three antigen mismatched cord blood transplant

**Note: for cord blood transplants - when you read the statistics, bear in mind that these types of transplants are relatively new and late effect mortality rate for such transplants are still not be known.

Golf Tournament

by Brian Clary

On July 14, 2007, we at the 'A Mile In Your Shoes' organization proudly hosted the 2nd Annual 18 Holes 4 Life Charity Golf Tournament at Fox Chase Golf Club in Lancaster, PA.

This annual event is held to raise awareness and funding for both prominent and lesser known cancer causes and to truly make a difference in the lives of those affected by these life-threatening diseases.

In 2007, all proceeds and contributions generated from this event, totaling more than \$7,500.00 were donated to Candlelighters Childhood Cancer Foundation to help support their Targeted Therapeutics initiative, whose mission is very much aligned with the goals we have set for ourselves.



As the widower of a cancer victim, I can attest first hand to the urgency and necessity of the awareness and contributions generated by such events. We send our sincere thanks to all the

volunteers, participants, and supporters who made this an extremely successful year, but most of all, we thank everyone involved with Candlelighters who help to make our voices heard.



A Message from Executive Director Ruth Hoffman MPH *continued*

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those children who do survive will face life-long late effects from the current toxic treatments. Biologic drugs have proven to be an effective weapon in the war on cancer for adults. Drugs such as Gleevec have been found to target just the cancer cell mutations and not the entire body. As such, these new class of drugs often referred to as 'magic bullets' or 'smart drugs' remain the most promising treatments for the future. Because conventional chemotherapy and radiation treatments are so dangerous to children, young cancer patients are depending on innovative biotech companies to continue to develop more effective and targeted treatments.

At this time, U.S. law does not provide an approval pathway for 'follow-on' or 'generic' versions of these products. Generic versions would be approved after the initial patents expire, and

would presumably be less expensive for patients. But it's not yet feasible to manufacture identical copies of complex proteins, and there are concerns that generics could be different enough to cause harm to a patient as opposed to curing their disease.

Even more worrisome, from the standpoint of children with cancer, is the impact the wrong kind of legislation could have on innovation. Kids with cancer need novel drugs that can treat and cure their disease. That's why we need to support legislation that rewards innovation and encourages development of new life-saving biologics for children with cancer. A law that encourages *more copies* and *less innovation* will not help the children and their families living with cancer.

Two competing bills have recently been

introduced in the House: the Waxman Bill is entitled: 'The Access to Life-Saving Medicine Act' and the Inslee Bill is entitled: '**Patient Protection and Innovative Biologic Medicines Act.**' I testified in support of the Inslee Bill, which increases incentives for biotech companies to develop biologics as a targeted therapy for children with cancer, as opposed to decreasing incentives. **I'm asking you to add your voice in support of the Inslee Bill by signing and mailing the attached letter which will be collected and forwarded to your Congressperson.**

I'm personally convinced that biotech innovation is the best hope for a true cure to childhood cancers. But kids can't fight cancer alone. They're depending on you and me to keep the

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The Geeks Lament

Please listen, sir, please hear me out,
before you walk away.

The sky is clear and weather fair
but I cannot play today.

True, I've scrolled perhaps a thousands words
of fictitious tears and heartbreak.

Still, the amount of agony I feel now
is more than I can take.

The mild sun is harsh, you see,
on complexion light as mine.

Though many a man has cried at my verse,
my coordination is not so divine.

My vocab is vast, my talent unmatched,
my writing is my passion.

Jerseys, shorts and athletic shoes
are not within my fashion.

I cannot throw discs to save my life,
I've never caught a ball.

I may be tall and thin and fit
but when I run, I trip and fall.

When I join a team, you've seen this too,
I simply cannot deny,
that every member of said team
will curse and swear and sigh.

Don't give me that look! You know it's all true.

I really must be excused.

For, oh! How much I should suffer,
if this plea is, thus, refused.

Carl Sandiego (pen name) was diagnosed 10 years ago with ALL. Some of the neurotoxins he received during treatment have left him with mild balance, coordination & processing issues which he makes up with strength & creativity. Now a freshman in high school, physical education is his most dreaded class.

A Message from Executive Director *continued*

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pipeline of innovative biologic drug development alive and well.

Here's what I'm asking you to do to help:

- 1) Clip the letter on the facing page.
- 2) Go to www.house.gov and enter your zip code to find your Representative's name.
- 3) Fill in the name of your Representative at the top of the letter, fill in your name and address at the bottom, and sign the letter.

Mail the letter back to me at:

Candlelighters Childhood Cancer Foundation
10400 Connecticut Ave., Suite 205
Kensington MD 20895
Or fax it to me at: 301-962-3521

Once I have everyone's letters, I will sort them by Representative/state and



Suicidal Thoughts *continued*

Continued from page 4

Will all childhood cancer survivors have suicidal thoughts?

No, studies of childhood cancer survivors consistently show that the majority of survivors do not have any significant distress or long-term problems adapting to life after cancer. While some childhood cancer survivors may be at risk, it is important to remember that 87% reported no suicidal symptoms.

What are the differences between cancer survivors with and without suicidal symptoms?

Survivors with suicidal symptoms tended to be younger when their cancer was diagnosed, diagnosed with leukemia, and treated with cranial radiation. Survivors with suicidal thoughts also reported more depression and hopelessness. Physical health variables, including pain, were also associated

deliver them as a group for maximum impact.

Thanks so much for getting involved! I encourage you to copy the following letter and pass it along to friend, family members, and colleagues. This is our opportunity to make our united voice heard ... because kids can't fight cancer alone! I'll update you on this important legislation in the next newsletter.

Sincerely,
Ruth Hoffman
Executive Director

P.S. If you want more background information about this issue, you can find my complete House Subcommittee testimony at: <http://www.candlelighters.org/testimony.stm>

with suicidal symptoms. In fact, even after accounting for differences in cancer treatment and emotional variables, those with suicidal thoughts reported lower physical health functioning and more pain than those without suicidal thoughts. This is significant because it suggests one of the reasons childhood cancer survivors are at risk for suicidal thoughts is because of health problems they experience as adults.

What are the next steps?

More studies are needed to examine the relationships between suicidal symptoms, cancer treatments and post-treatment health. Currently, the Childhood Cancer Survivor Study is examining a large group of cancer survivors to better understand the relationship of cancer and physical health variables to suicidal thoughts.

The Honorable _____
United States House of Representatives
Washington, DC 20515

RE: H.R. 1956: Patient Protection and Innovative Biologic Medicines Act of 2007

Dear Mr. (Mrs., Ms.) _____:

As one of your constituents, and as a member of Candlelighters Childhood Cancer Foundation, I am writing to ask that you cosponsor and vote for H.R. 1956.

This matter is very important to me. Children suffering with cancer need access to breakthrough therapies which can actually treat and ultimately cure their disease.

As Ruth Hoffman, Executive Director of the Candlelighters, testified before the House of Representatives Energy and Commerce Subcommittee on Health, children with cancer continue to be treated solely with highly toxic cancer drugs that were developed 20 to 30 years ago. While enormous progress has been made in developing treatments for other conditions, treatments for childhood cancer have remained stagnant. Survivorship for children with cancer has not increased in ten years.

However, there is hope: biologic drugs have shown promise in treating cancer. At this critical time, it is vital that we spur innovation for pharmaceutical companies to invest in the development of these life saving drugs. Currently, there are two main proposals before Congress that would create a pathway for follow on biologics. H.R. 1038, the 'Access to Life-Saving Medicine Act' which was introduced by Congressman Henry Waxman (D-CA), would greatly hinder innovation and divert attention away from investing in the discovery for new medications.

H.R. 1956, the 'Patient Protection and Innovative Biologic Medicines Act of 2007,' which was introduced by Congressman Jay Inslee (D-WA), Tammy Baldwin (D-WI), and Gene Green (D-TX), and currently has 14 co-sponsors, establishes an appropriate balance between reducing cost and providing incentives for innovation. It is this proposal which will provide hope to children suffering from cancer, and which I strongly urge you to support.

Please cosponsor and vote for H.R. 1956!

Yours truly,

Name:

Address:



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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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Link to Candlelighters Childhood Cancer
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