The Neuroblastoma Children’s Cancer Society

Vol. 18, No.1
Summer 2014

An informative newsletter to educate, support, and increase awareness

CHILDREN ARE OUR FUTURE! THEY ARE THE RAINBOW THAT MAKE OUR DAYS BRIGHT

HOPE for more tomorrows for children with Neuroblastoma is the theme of the Neuroblastoma Children’s Cancer Society. HOPE stands for the following:

H elp for Children and their Families
O ncology Research
P ublic Awareness
E ducation

In Honor of...Jackson Katterhagen

State: Wisconsin
Pets: Dog named Camo
Favorite place: Zoo
Favorite thing: Toy Story toys
Favorite movie: Toy Story
Favorite song: Twinkle Twinkle Little Star
Something special: Jackson is an amazing child. He never gives up and is always smiling. He loves to give hugs and kisses and tell you he loves you. While in the hospital he became very close to his nurses. He called them all "ladies" and the guys were "dudes"!!! They loved it. He was declared NED in November 2012 and has remained cancer-free at this time. We pray everyday he will always remain cancer-free.

http://www.youtube.com/watch?feature=player_detailpage&v=aQgtgLxmtD8

The Neuroblastoma Children’s Cancer Society is a group of volunteers, many with children or relatives who have been both victims and survivors of the disease. The Organization is an advocate for the children and their families and is dedicated to providing support. The primary focus of the Organization is to raise money to assist local research in neuroblastoma cancer and to bring the fight to a national level to try and focus additional research and funding until a cure can be found!
The Neuroblastoma Children’s Cancer Society

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Dori Sexton, President
Jim Sexton, Chairman
Kenna Anderson, Vice President
Monica Faucheux
Cathy Crivellone
Lou Williams
Renee Williams
Dr. Susan Cohn *
Dr. Samuel Volchenboum *

* Designates Honorary Board Members

GUIDE TO INTERNET CONNECTIONS

Please note that some of this information is the most current that is available, while some is not always updated regularly, particularly medical information.

AMERICAN BRAIN TUMOR ASSOCIATION HOMEPAGE:
http://www.abta.org

AMERICAN SELF-HELP CLEARINGHOUSE: Self-Help Group Sourcebook Online: Information on national and model self-help support groups, clearinghouses, organizations, and resources:
http://www.medhelp.org/selfhelp/

CANCER KIDS WEBSITE: http://orear.com/cancerkids/

NATIONAL CANCER INSTITUTE: http://www.cancer.gov

CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION:
https://www.candle.org

ANN & ROBERT H. LURIE CHILDREN’S HOSPITAL OF CHICAGO:
https://www.luriechildrens.org/

THE UNIVERSITY OF CHICAGO MEDICINE COMER CHILDREN’S HOSPITAL:
http://www.uchicagokidshospital.org

HISTIOCYTOSIS ASSOCIATION OF AMERICA: The goals of this organization include public and professional education, patient and family support, and support of research: https://www.histio.org

FRIENDS OF KIDS WITH CANCER: https://www.friendsofkids.com

MEDHELP INTERNATIONAL: http://www.medhelp.org

AMERICAN CHILDHOOD CANCER FOUNDATION:
http://www.acco.org

NATIONAL HEALTH INFORMATION CENTER (NHIC): This website is managed by the NHIC, a government sponsored health information referral service. http://www.health.gov/nhic/

NEUROBLASTOMA CHILDREN’S CANCER SOCIETY: Provides information on neuroblastoma for families of children diagnosed with this form of cancer: http://www.neuroblastomacancer.org

CHILDREN’S ONCOLOGY GROUP:
http://www.childrensoncologygroup.org

INFORMATIONAL SITES ON THE INTERNET:
http://www.cdc.gov/cancer/

Newsletter Generously Funded by:
We need a sponsor for our newsletter!

Note from the Editor

The views contained in the articles of this newsletter are the opinions of the authors. The editor and Neuroblastoma Children’s Cancer Society are not in any way affiliated and make no attestation in support (or against) the information supplied in these articles.

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Metastatic neuroblastoma confined to distant lymph nodes (stage 4N) predicts outcome in patients with stage 4 disease: A study from the International Neuroblastoma Risk Group Database


**Purpose**

The presence of distant metastases is one of the most powerful predictors of outcome in patients with neuroblastoma. However, the pattern of metastatic spread is not incorporated into current risk stratification systems. Small case series have suggested that patients with neuroblastoma who have metastatic disease limited to distant lymph nodes (4N disease) may have improved outcomes.

**Patients and Methods**

We analyzed retrospective data from the International Neuroblastoma Risk Group database for patients diagnosed from 1990 to 2002. 4N patients were compared with the remaining stage 4 patients (non-4N), excluding those with missing metastatic site data.

**Results**

In all, 2,250 International Neuroblastoma Staging System stage 4 patients with complete data were identified, of whom 146 (6.5%) had 4N disease. For 4N patients, event-free survival (EFS; 5-year, 77% ± 4%) and overall survival (OS; 5-year, 85% ± 3%) were significantly better than EFS (5-year, 35% ± 1%) and OS (5-year, 42% ± 1%) for non-4N stage 4 patients (P < .001). 4N patients were more likely to be younger (P < .001) and have tumors with favorable characteristics, including absence of MYCN amplification (89% v 69%; P < .001). In a multivariate analysis, 4N disease remained a significant predictor of outcome (hazard ratio for non-4N v 4N: 3.40 for EFS and 3.69 for OS). Within subgroups defined by age at diagnosis and tumor MYCN status, 4N disease was significantly associated with improved outcomes.

**Conclusion**

4N represents a subgroup with better outcome than that of other patients with metastatic disease. These findings suggest that the biology and treatment response of 4N tumors differ from other stage 4 tumors, and less intensive therapy should be considered for this cohort. Future exploration of biologic factors determining the pattern of metastatic spread is warranted.

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**Wall of Fame Sponsors**

Please help us by sponsoring one of our children and build our WALL of FAME!! The response to our survey and WALL OF FAME has been overwhelming. We have had over 200 families respond with pictures, drawings, surveys, etc. and they are still rolling in. Come visit our internet WALL of FAME being built and see our little celebrities, our children. Now we need your help to complete this project. The wall is now complete and we have over 200 children who represent the thousands of U. S. families affected by neuroblastoma. Please help by sponsoring or finding sponsors for these children. If we can raise $2,500 for each child, we will have raised over $250,000, 100% of which will be used for a neuroblastoma research grant.

Let us build this WALL OF FAME and provide HOPE for these children! Together we can make a difference!

My tax deductible contribution is enclosed:

☐ $25,000  ☐ $2,500  ☐ $1,000  ☐ $500  ☐ $100  ☐ Other $

☐ Research Sponsor  ☐ Child Sponsor  ☐ Honor  ☐ Memory

Child’s Name ________________________________

Donations can be made online through PayPal. Go to our web site at www.neuroblastomacancer.org.

For all donations: My name is ________________________________

Address _____________________________  City __________________  State _____  Zip _____

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Neuroblastoma HOPE
Friends of Michael Williams 12th Annual Golf Outing Raises $25,000 to fund neuroblastoma research

Dr. Susan Cohn,
University of Chicago
Chicago, IL

Dear Dr. Cohn:

The 12th Annual 'Friends of Michael Williams' Fund-Raiser raised close to $25,000. 'Friends of Michael Williams' is a chapter of the Neuroblastoma Children's Cancer Society. NCCS matched the proceeds in the amount of $25,000 which includes 2013 and prior donations, memorial gifts, etc.

We are pleased to announce that you, in connection with the University of Chicago Hospital, are the recipient of our annual research grant for neuroblastoma research totaling $50,000! We want this to help support the Interactive International Neuroblastoma Information Network directed by Dr. Cohn.

We appreciate your dedicated work and support of neuroblastoma research. It is our hope that our grant will give you the financial means to support the research that will lead to a cure for neuroblastoma! Best of Luck!

Warmest Regards,

James F. Sexton
Chairman

Dori Sexton
Executive Director
Friends of Michael Williams
cordially invites you to
The 13th Annual Golf Outing
Saturday, September 20, 2014
Glenwoodie Golf Course
19301 South State Street, Glenwood, IL • (708) 758-1212

Registration begins at 11:00 a.m. • Doves released at 1:00 p.m. • Dinner at 6:00 p.m.

Kindly RSVP as soon as possible (reservations on a first come/first served basis)

Proceeds to Benefit The Neuroblastoma Children's Cancer Society
An advocate for stricken children and their families, the primary focus of this Society is to raise money to assist research in Neuroblastoma. The Society hopes to bring the fight to a national level to increase funding for additional research for a cure. Friends of Michael Williams supports this effort.

Yes, I want to help The Neuroblastoma Children's Cancer Society fund research for new treatments in the fight against neuroblastoma and provide support for patients and their families.

My tax-deductible contribution is enclosed.

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<th>Option</th>
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<td>General Donation</td>
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<td>Golf only ($140 per golfer)</td>
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<td>Raffle Tickets*</td>
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<td>$5 each, 5 for $20, and 30 for $100</td>
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<td>Raffle Ticket order needs to be received by September 18</td>
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*Mail-in Raffle Prizes—$250, $100, $50 gift cards

For All Donations:

My name is ________________________________
Address ___________________________________
City ___________________ State _______ Zip ___

NCCS, Friends of Michael Williams
c/o Beth Possley
P. O. Box 957672
Hoffman Estates, IL 60169-7672
(630) 832-1847

Neuroblastoma HOPE
UNIVERSITY OF CHICAGO'S GRANT THANK YOU

October 5, 2013

Mr. James Sexton, Chairman
Neuroblastoma Children's Cancer Society
P.O. Box 957672
Hoffman Estates, IL 60195

Dear Jim:

I would like to thank you for being such a strong supporter of neuroblastoma research at the University of Chicago Medicine. I am deeply grateful for your thoughtful donation from the recent Friends of Michael Williams Golf Outing which will allow me and my colleagues to further our important work. Your generosity demonstrates your deep commitment to advancing neuroblastoma research with the hopes of finding a cure, and I greatly appreciate your support.

I am thankful for all that you have done on behalf of our littlest patients. I hope that we will soon make ground-breaking scientific discoveries that will allow us to cure such devastating pediatric cancers. Once again, please accept my deepest gratitude for your invaluable support. Please let me know when we can schedule a visit to the University of Chicago to discuss our studies and progress in more depth.

Sincerely,

Susan L. Cohn, MD
Professor and Director
Clinical Sciences
Department of Pediatrics
Section of Pediatric Hematology/Oncology
University of Chicago

SPECIAL THANK YOU TO OUR CONTRIBUTORS

Major Contributors
St. Teresa of Avila
BP Amoco
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Fred & Jean Stevens

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Brian & Grace Klimes
Tom Kluber
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MEMORIAL OR HONOR GIFT REQUEST

Your Name: _______________________________
Address 1: ____________________________________________
Address 2: ____________________________________________
City: ___________________________ State: ______ Zip: _______
Phone: ______________________________

☐ In Memory Of ☐ In Honor Of ☐ On the Occasion Of _________________________

Name: ______________________________

I would like an acknowledgement gift card sent to:
Name: ______________________________
Address 1: ____________________________________________
Address 2: ____________________________________________
City: ___________________________ State: ______ Zip: _______

How do you wish the card to be signed? ______________________________

Enclosed Gift Amount: ______________________________

Send form and payment to: NCCS, P. O. Box 957672 • Hoffman Estates, IL 60195

Donations also can be made online through PayPal. Go to our web site at www.neuroblastomacancer.org.
Runners and walkers anywhere in the world are invited! Simply complete 5K distance (3.11 miles) at any time between November 24th and November 29th. If you are already signed up for a Thanksgiving race you are welcome to count your race time towards this one as well! To register for the event and to share your race time and photos to the event page at https://www.facebook.com/events/796125667074201/. Prizes awarded for most creative outfits and a general raffle for all participating to win Amazon gift cards!

To enter submit donation of $30 to PayPal at http://www.neuroblastomacancer.org/donate.php with your address and e-mail address. Every entry received by November 14th will receive a race bib in the mail along with a keepsake towel.

**Congress Passes Pediatric Research Laws: A Step Forward for Children with Cancer**

The United States Senate approved legislation that will improve research and development of new drugs for children with cancer. "We are pleased that Congress has responded to the pleas of the Children's Cause for Cancer Advocacy urging a more aggressive federal role in encouraging research on life-saving childhood cancer therapies," said Maureen Lilly, executive director of Children's Cause.

The action of the Senate followed House of Representatives approval of legislation renewing the user fee programs for the Food and Drug Administration (FDA) and authorizing additional activities of FDA. The user fee legislation is on its way to President Obama for his signature.

The federal government has for a number of years encouraged, and in some cases, required research on new drugs for all pediatric diseases. The bill permanently reauthorizes the two pediatric research programs, the Pediatric Research Equity Act and the Best Pharmaceuticals for Children Act.

Although the laws have generally worked well in encouraging pediatric research, they have had a limited impact on pediatric cancer drug development. Given these realities, Children's Cause focused in this legislation on the need for the PDA to pay special attention to the benefit of the laws for pediatric cancer research.

"We are very pleased that the door has now been opened for pediatric cancer diseases to receive the special attention they were not receiving before," Lilly said. "We must never forget that pediatric cancer is the number one disease killer of children in the United States."

Children's Cause looks forward to completion of the FDA's report on pediatric research laws and offers its assistance to FDA in its special assessment of the impact of the laws on pediatric cancer drug development.

"We will do all we can to publicize and act on the recommendations of the report and its plan for strengthening the laws and their ability to foster pediatric cancer drug development." Lilly said.

In addition, the legislation approved by Congress also enhances the reporting requirements that are imposed on pharmaceutical companies that experience shortages of drugs. In the past year, children with cancer and their caregivers have suffered through life-threatening shortages of key pediatric cancer therapies. Children's Cause commends Congress for including drug shortages solutions in the user fee legislation and will carefully monitor the benefits of the law's drug shortages provisions.

Children's Cause for Cancer Advocacy (CCCA) is a leading national advocacy organization that works to achieve access to less toxic and more effective therapies, expand resources for treatment and address the needs and challenges of childhood cancer survivors and their families. CCCA works to ensure that these needs and perspectives are integrated into the highest deliberations of cancer policy.

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**Give Neuroblastoma The Bird**

The Neuroblastoma Children’s Cancer Society presents…

“Give Neuroblastoma The Bird” Virtual 5K

To register for the event and to share your race time and photos to the event page at https://www.facebook.com/events/796125667074201/.

Runners and walkers anywhere in the world are invited! Simply complete 5K distance (3.11 miles) at any time between November 24th and November 29th. If you are already signed up for a Thanksgiving race you are welcome to count your race time towards this one as well!

To enter submit donation of $30 to PayPal at http://www.neuroblastomacancer.org/donate.php with your address and e-mail address. Every entry received by November 14th will receive a race bib in the mail along with a keepsake towel.
Whipping Childhood Cancer Challenge

The Neuroblastoma Children’s Cancer Society challenges YOU to “Whip Childhood Cancer”!

A person who is challenged has 46 hours to get a pie (whipped cream or shaving cream) to the face and donate $7 or opt out and donate $46. Why 46/7? Our aim is to raise awareness that on average, 46 children are diagnosed with pediatric cancer a day and 7 lose that battle daily. Help us change those statistics and take the challenge!

The final step of the challenge is simple. Just share your video on Facebook (to “The Neuroblastoma Children’s Cancer Society” group) and Twitter with #WhippingChildhoodCancer as the hashtag so that we can cheer you on! And don’t forget to tag either 7 friends or better yet 46 friends depending on whether you completed your challenge in 46 hours. You can make donations at http://www.neuroblastomacancer.org/donate.php.

September is National Childhood Cancer Awareness Month. Join the challenge and our commitment in fighting childhood cancer.