

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:

Help for Children and their Families
Oncology Research
Public Awareness
Education

IN MEMORY OF... VICTORIA LOVE HOUSTON



State: Tennessee

My Family: Mom, Dad, Sister Abigail,
Brother Micah

Favorite place: Home

Favorite thing: Jumping on trampoline
with her sister

Favorite movie: *The Grinch*

Favorite song: "O Holy Night"

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!

HOPE

Address Corrections Requested

Hoffman Estates, IL 60195-7672
P. O. Box 957672

Children's Cancer Society
The Neuroblastoma



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Those areas in bold will be the focus of our quarterly newsletter. Please send in your ideas, articles, requests, special stories and pictures to: The Neuroblastoma Children's Cancer Society
P. O. Box 957672 • Hoffman Estates, IL 60195

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** In memoriam

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 HOME PAGE:

www.abta.org

AMERICAN SELF-HELP CLEARINGHOUSE, SELF-HELP SOURCE-
BOOK ON-LINE: Information on national and model self-help support
groups, clearinghouses, organizations, and resources — www.cmhc.com/self-help/

CANCER KIDS WEBSITE: www.cancer.org

CANCERNET and PDQ: This website is managed by the National Cancer
Institute and provides information on cancer treatment, supportive care,
and advocacy — www.cancernet.nci.nih.gov

CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION: Links to
other information and resources on childhood cancer.
www.candlelighters.org

CHILDREN'S MEMORIAL HOSPITAL
www.childmmc.edu/cmhweb/default.htm

UNIVERSITY of CHICAGO COMER CHILDREN'S HOSPITAL
www.uchicagokidshospital.org

HISTIOCYTOSIS ASSOCIATION OF AMERICA: The goals of this orga-
nization include public and professional education, patient and family
support, and stimulation and support of research — www.histio.org

KIDS WITH CANCER — www.kidswithcancer.com

MEDHELP INTERNATIONAL: An extensive brain tumor library — <http://medhlp.netusa.net>

NATIONAL CHILDHOOD CANCER FOUNDATION (NCCF): Describes
NCCF and offers a listing of CCG clinical cooperative group protocols
— www.nccf.org/

NATIONAL HEALTH INFORMATION CENTER (NHIC): This website
is managed by the NHIC, a government sponsored health information
referral service. Offers direction to other organizations and resources
— <http://nhic-ht.health.org>

NEUROBLASTOMA CHILDREN'S CANCER SOCIETY: Provides informa-
tion on neuroblastoma for families of children diagnosed with this form
of cancer — www.neuroblastomacancer.org

PEDIATRIC ONCOLOGY GROUP (POG): www.pog.ufl.edu/main.html

INFORMATIONAL SITES ON THE INTERNET: www.acor.org;
<http://cancer.med.upenn.edu/> www.cancer.org
<http://cancerguide.org/bonemarrow.html>

Newsletter Generously Funded by:

**We need a sponsor for our
quarterly 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.



THE NEUROBLASTOMA VIRTUAL TUMOR BANK (VTB)

2008 SUMMARY OF ACCOMPLISHMENTS

The funding provided by The Neuroblastoma Children's Cancer Society (NCCS) has made it possible to perform the following national and international work which falls outside the scope of the Children's Oncology Group:

1. Development of a computer SAS macro for faster specimen selection for national and international laboratory research projects;
2. Generation of 16 statistical technical reports, including one that resulted in a paper accepted to the prominent, high-impact journal *Nature*;
3. Addition of data to differentiate patients who died of their neuroblastoma from those who have died from some other cause (toxicity or accidental cause);
4. Addition of data to track which patients' data are used on which project in order to avoid using a given patient's data for both hypothesis generation and validation;
5. Updating the database with more recent information about the duration of time that the patients have survived;
6. Incorporation of new data from the Biopathology Center's FreezerWorks database and the Children's Hospital of Philadelphia; and,
7. Generation of detailed documentation of the system of programs required to support and maintain the VTB data, as well as to document the database structure.

1. Macro for specimen selection

Until recently, much of the process to select specimens from the Virtual Tumor Bank (VTB) database was manual. The funding from NCCS allowed us to develop a more automated computer SAS macro for consistent and efficient selection of specimens. Eligibility criteria are used to define a subset of patients' specimens from the VTB database, and then specimens are randomly selected from that subset. We now have a macro template that can be easily modified for a given specimen selection request. The new macro permits the selection process to be done in a very short period of time; therefore, the research process for a cure has been accelerated.

Specimen selection was made for 20 projects, each performed with a two-day turnaround time from the time of request.

As of December 3, 2007, the total number of tumor specimens

with complete outcome data that were available for selection for laboratory research projects was 4,021.

2. Generation of statistical technical reports

The statistical analysis of investigator-initiated correlative biology studies is work that is not funded by the COG. With the funding from the NCCS, we have performed specimen selection on 20 projects, and been able to provide 16 technical reports over the past year. The data from the VTB (survival dataset and the biology dataset) are linked to the laboratory results and analyzed. The results are communicated back to the investigators in the form of statistical technical reports. Subsequent to the technical reports, we have collaborated on 10 manuscripts for journal publication in the last year, including a manuscript currently in press with the prominent, high-impact journal *Nature*.

3. Identification of patients who died from neuroblastoma

For clinical trials, a bad outcome of any kind is typically used as a measure of the lack of benefit of a given treatment. However, in biological studies of the natural history and genetic causes of neuroblastoma, it is important to analyze only the disease-related bad outcome, and exclude deaths that were due to toxicity or accidents. In other words, we need to be able to tell if the patient died of the disease rather than just knowing they died. Based on this information, another dataset is in the process of being developed that will allow calculation of progression-free survival (PFS) rates in addition to the event-free survival (EFS) more typically employed in clinical trials. This will be very important for the analysis of national and international microarray data projects.

4. Track use of specimens by project

A program and database have been added that allows us to keep track of which patients were selected for a given project. This information is critical in order to prevent using a given patient's data for both hypothesis generation and validation of a neuroblastoma gene or risk factor. For example, the patients from Dr. John Maris's TARGET project (a full genome study that will be used to identify genetic mutations as potential therapeutic targets), will be excluded from possible selection on any other project with similar goals.

5. Update survival duration data

The overall survival dataset used for analysis was updated to include the most recently activated COG protocols, and this allows

(continued on page 5)



TREATMENT AND RESEARCH



UNIVERSITY OF CHICAGO HOSPITAL IS THE RECIPIENT OF NCCS'S ANNUAL RESEARCH GRANT



September 19, 2008

Dr. Susan Cohn
University of Chicago
5841 Maryland Avenue
MC 4060, Room N114
Chicago, IL 60637

Dear Dr. Cohn:

The 7th Annual 'Friends of Michael Williams' Fund Raiser is expected to raise over \$25,000. 'Friends of Michael Williams' is a chapter of the Neuroblastoma Children's Cancer Society. NCCS matched the proceeds in the amount of \$35,000.

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 \$60,000!

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



September 30, 2008

Neuroblastoma Children's Cancer Society

Thank you for directing the Neuroblastoma Children's Cancer Society's generous match of the 'Friends of Michael Williams' gift to support my research at the University of Chicago. Your continued support has great impact on my neuroblastoma research, allowing me to work in collaboration with other Chicago investigators to better understand and more effectively treat neuroblastoma.

One such collaboration is with Lucy Godley, M.D., Ph.D., on a project evaluating abnormal methylation in neuroblastoma tumors. Our preliminary results indicate that we may have identified a truncated enzyme (short protein) that may modify gene methylation and alter the aggressiveness of tumor growth. To date, we have shown that if we overexpress this truncated protein in neuroblastoma calls, we can dramatically reduce tumor growth in mice.

We are also collaborating with a number of other investigators at the University of Chicago to test a variety of new drugs using our neuroblastoma model, including inhibitors of the ALK gene. These studies are also yielding very exciting results.

Sincerely,

Susan L. Cohn, MD
Professor and Section Chief
Institute for Molecular Pediatric Sciences
Department of Pediatrics
Section of Hematology/Oncology
University of Chicago

\$\$

FUND-RAISERS

\$\$



Friends of Michael Williams 7th Annual Golf Tournament Supports \$60,000 Research Grant



DR. SUSAN COHN IS PRESENTED WITH A \$60,000 CHECK BY HANK AND BETH POSSLEY AND LOU AND RENEE WILLIAMS OF FRIENDS OF MICHAEL WILLIAMS, ALONG WITH NCCS BOARD MEMBERS JIM AND DORI SEXTON AND CATHY CRIVELLONE.



Neuroblastoma Virtual Tumor Bank *(continued from page 3)*

accurate follow-up for patients who enroll on multiple studies either sequentially or simultaneously. This required incorporating several datasets for each new study, including information from several sources, each with a different way of formatting variables.

6. Adaptation to changing data inputs to the VTB

The Biopathology Center (BPC) has changed the way they collect and disseminate their data, separating the data into older data representing all the neuroblastoma legacy data, and newer data in a system called FreezerWorks. We have made changes to our programs and data structure to adapt to these improved inputs. In addition, the format and content of the data transmissions from the Children's Hospital of Philadelphia has changed, and required a significant programming effort.

7. Documentation of the VTB database structure and computer programs

A continuous work in progress is maintaining an up-to-date detailed description of each part of the VTB database structure and system of computer programs. This documentation shows the location of the various files and data along, which programs are run to create the various datasets, and the names of the datasets. In addition, key datasets are copied to a shared drive in order to permit sharing of the data and programs by other statisticians in COG.

For a table showing specimens in the Neuroblastoma Virtual Tumor Bank (VTB), please contact the Neuroblastoma Children's Cancer Society at P. O. Box 957672, Hoffman Estates, IL 60195-7672.

For a list of manuscripts generated from data and/or specimens from the VTB, please contact the Neuroblastoma Children's Cancer Society at P. O. Box 957672, Hoffman Estates, IL 60195-7672.



FUND-RAISERS



NCCS would like to offer you the opportunity to recognize your friends and loved ones and help NCCS at the same time. We have honorary and memorial cards available to send out on your behalf.

Contributions may be given in memory of a loved one or in honor of special occasions such as birthdays, graduations, holidays, anniversaries, etc. Call the NCCS office for more information ... (800) 532-5162.

NATIONAL CANCER INSTITUTE
CANCER INFORMATION SERVICE
1-800-4-CANCER
(1-800-422-6237)

- Tips to prevent cancer
- Informational Materials
- Answers to questions about cancer
- Other Resources

www.cancer.gov/publications

United Way is not just about giving ... it's about caring

You can designate that your contribution be given to NCCS.

Call us at our office for details (800) 532-5162.

IN HONOR OR MEMORY OF...

We have received many contributions in memory of children lost (but not forgotten) to neuroblastoma and in honor of children in the battle of treatment with neuroblastoma. It is these children that inspire our relentless effort to find a cure.

We also receive donations for special occasions, in honor or memory of family members and loved ones. Rest assured this money will be put to meaningful research. It is in honor and memory of our children that we continue the battle for a cure!

In Memory of:

Victoria Love Houston

Our sincere gratitude to and acknowledgement has been sent to Family and Friends.

RECOGNIZE A BIRTHDAY, ANNIVERSARY, OR SPECIAL OCCASION WITH A GIFT OF LOVE! (You can find this page on our web site!)

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? _____

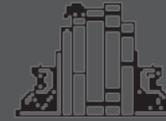
Enclosed Gift Amount: _____

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.



RESOURCES



Thank You! Thank You!

We recognize and give a “big hug” and thank you to our recent contributors:

Mr. & Mrs. William Amster

Ms. Sharon Bending

Mr. & Mrs. Roger Bielinski

Dr. Charles Boyajian

Mr. & Mrs. Larry Cohen

Mr. John Peter Curielli

Ennes & Associates, Inc.

Mr. & Mrs. Ronald Glaser

Mr. Christopher Kalmus

Ms. Luanne King

Mr. Brian Klimes

Mr. Larry Malinowski

Mr. & Mrs. Dan Nagle

Ms. Nancy Partipilo

Mr. Tony Partipilo

R. B. Roaper

Drs. Sheehy, Bielinski and Griffin,
Urology, Ltd.

Mr. & Mrs. William Veschuroff

Woodlawn Engineering Company, Inc.

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FOCUS ON RESOURCES

CANCER PATIENTS FLY FREE... IN EMPTY SEATS ON CORPORATE JETS

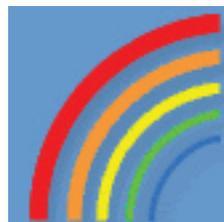


A message for cancer patients of all ages. You can fly to recognized treatment centers around the country – *absolutely free* – in the empty seats on corporate jets. No costly airfare. No stressful delays. No unnecessary exposure to airport crowds. **Corporate Angel Network**, a national public charity, works directly with patients and families to coordinate their travel needs with the flight plans of their Corporate Angels, some of the nation's largest corporations. Since 1981, they've arranged more than 25,000 flights with cancer patients aboard.

Give them a call [patient toll free (866) 328-1313]. They'll do all the work.

Corporate Angel Network, Inc.

Westchester County Airport, One Loop Road, White Plains, NY 10604
(914) 328-1313 • Info@CorpAngelNetwork.org



THE NEUROBLASTOMA CHILDREN'S CANCER SOCIETY ON-LINE RESOURCE SURVIVAL HANDBOOK

THE NEUROBLASTOMA CHILDREN'S CANCER SOCIETY PRESENTS RESOURCE SURVIVAL HANDBOOK FOR FAMILIES WITH CHILDREN WITH NEUROBLASTOMA CHILDREN'S CANCER.

This handbook has accumulated a resource of information of facts about neuroblastoma and related treatments, national and local resources available to families, patient history and treatment forms, health claim forms, pamphlets, etc.

This book was prepared and dedicated in honor of the life of Michael James Sexton, whose determination and purpose in his fight against neuroblastoma has given many the courage and spirit to continue the battle.

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Information On Our Organization	Insurance Claim Record Form
Facts About Neuroblastoma	Patient's Information
Facts: Neuroblastoma and Related Treatments	Patient's History and Other Important Information
Glossary of Terms	Important Phone Numbers
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National Resources	Treatment Journal
Local Resources	Children's Memorial Hospital Chicago
Pamphlets and Books	Family Survey Form
	Health Claim Assistance



OUR SPECIAL CHILDREN



IN HONOR OF...

PRINCESS BELLA

CAITLYN MICHELLE MCGUIRE



I live in: Virginia

Family: Mother Nichole; Brother Dominic

Something special about Princess Bella:

This beautiful child was a gift from the Lord two days before Christmas and her birth alone brought our family back together. Then with her diagnosis, it seems like the Lord was telling us something. She is doing well and was

an absolute hero during chemo. She took her first steps on Halloween which she was a good witch =>) I just know that everyone who sees her and knows she has cancer loves her so much at first sight. The type of love that makes the back of your throat hurt. She is an amazing baby and just makes you happy when you see how well she is and is on the fourth stage of her cancer, but the Lord is good because she is healthy and happy. To all who are going through this, I will tell you like I told my niece: I admire your strength. When I see Bella I want to cry so bad because I know she is sick and she doesn't. I want to cry but can't because her mother who is my niece has cried so much she can't shed anymore tears but still smiles because she spends every second of the day with her children now because she values her life and her family. I hope I have the strength that she has when I need it. God bless you all, and I will keep everyone in my prayers.



I live in: Pennsylvania

Family: Mom, Dad, Sister, Grandparents, Aunts, and Uncles

My pets: Three dogs and some fish

My favorite place: Sesame Place

Favorite thing: My dolls

Favorite movie: *Short Circuit*

Favorite song: She has so many

About Caitlyn: With all that she has gone through she still tries to be a great big sister and stays strong for her family.

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 _____