

*An informative newsletter to educate, support, and increase awareness*

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

**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...SOFIA CANALE



*I live in:* California

*Family:* Mom, Dad, Brothers Joey and Max

*Pets:* Two dogs; two snakes, goldfish

*Favorite place:* Home

*Favorite movie:* Baby Einstein

*Favorite song:* Itsy Bitsy Spider

**About Sofia:** Sofia is our princess. We could not ask for a happier baby. Her older broth-

ers make her the center of attention. Her smile lights up the room. She is now seven months and ready to move about. We are grateful her cancer was caught at an early stage. She is an angel, and we are blessed.

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

**The Neuroblastoma  
Children's Cancer Society**



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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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**Newsletter Generously Funded by:  
Innovating Worthy Projects Foundation  
THANK YOU!**

### 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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\*\* 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](http://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/](http://www.cmhc.com/self-help/)

CANCER KIDS WEBSITE: [www.cancer.org](http://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](http://www.cancernet.nci.nih.gov)

CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION: Links to other information and resources on childhood cancer. [www.candlelighters.org](http://www.candlelighters.org)

CHILDREN'S MEMORIAL HOSPITAL  
[www.childmmc.edu/cmhweb/default.htm](http://www.childmmc.edu/cmhweb/default.htm)

UNIVERSITY of CHICAGO COMER CHILDREN'S HOSPITAL  
[www.uchicagokidshospital.org](http://www.uchicagokidshospital.org)

HISTIOCYTOSIS ASSOCIATION OF AMERICA: The goals of this organization include public and professional education, patient and family support, and stimulation and support of research — [www.histio.org](http://www.histio.org)

KIDS WITH CANCER — [www.kidswithcancer.com](http://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/](http://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 information on neuroblastoma for families of children diagnosed with this form of cancer — [www.neuroblastomacancer.org](http://www.neuroblastomacancer.org)

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

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



## NCCS RESEARCH GRANTS TOP \$1 MILLION

With the continued financial support of family and friends touched by children with neuroblastoma cancer, as well as numerous fundraisers, including the *Friends of Michael Williams* annual golf outing, and two one-time grants from the Tom Russell Charitable Foundation and the Estate of James Hampton, the Neuroblastoma Children's Cancer Society was able to fund national research projects for the first time this past fiscal year.

With major federal cutbacks, the National Institute of Health (major funder of pediatric cancer research) has made and proposed major research cutbacks to Phase I clinical trials. Furthermore, promising research to further genome lab studies, genetic profiling, etc. have been eliminated at such a critical time when we are on the verge of breakthrough research to win the battle and loss of children to neuroblastoma, the major pediatric cancer with the worst prognosis for long-term survival.

That is why grass roots efforts from groups such as NCCS become so critically important at this time of need. With the two latest grants of \$60,000 to Dr. Susan Cohn's research at the University of Chicago and \$50,000 to Wendy Landor, Ph.D. Associate Professor at the University of Florida to support the Neuroblastoma Virtual Tumor Bank (NVTB), NCCS grants for fiscal year ended June 30, 2007, have exceeded \$200,000 and have topped over \$1 million neuroblastoma research grants directly from NCCS. With two earlier grants to Childrens Hospital Los Angeles, not only has NCCS extended its research grants from coast to coast, the research supported has filled a gap from budget cuts and supported genome lab research, genetic profiling, and Phase 1 clinical trials in neuroblastoma. NCCS is having an international impact on neuroblastoma research and advancement. ***Thank you for your support and for making a difference!***

April 10, 2007

Neuroblastoma Children's Cancer Society

I write in appreciation of the recent grant from the Neuroblastoma Children's Cancer Society to support Dr. Susan Cohn's research in the Division of the Biological Sciences. I am pleased that the University can work closely with the foundation to improve treatments and care for our young cancer patients.

On behalf of the University of Chicago, thank you again for your generous commitment to our doctors and scientists.

Robert J. Zimmer, President, The University of Chicago

March 29, 2007

Mr. and Mrs. James Sexton

The Neuroblastoma Children's Cancer Society

I wanted to let you know that we received your check totaling \$60,000. Thank you again for your generous support. We have several new studies that will be published in the next few months in cancer research journals, and I will forward the reprints once they are published. We would not have been able to complete these laboratory studies without your support.

The University of Chicago is a very exciting place to work. There are many talented scientists here who are researching various types of cancer, and I am looking forward to collaborating with these investigators to develop better therapies for children with neuroblastoma. I am also developing the clinical research program in the Department of Pediatrics and the Section of Hematology/Oncology. We have opened over 30 new COG studies and the NANT studies will be open for patient enrollment next week. I am working closely with the adult oncology Phase I program that is examining a number of new agents for cancer patients, and we have amended several adult studies so that teenagers can now receive some of the exciting new targeted therapies.

Our group is also developing innovative stem cell transplant protocols, and we are working closely with many of the other specialists at the University of Chicago to develop a comprehensive long-term survival program.

I'd love to have you visit for a tour of the new hospital and labs. I'd also like to talk further with you regarding the national database you are interested in establishing. Please let me know when you'd like to meet or talk by phone to discuss this.

Susan Cohn, MD, Professor of Pediatrics  
Chief, Section of Clinical Sciences • Institute for Molecular  
Pediatric Sciences • University of Chicago

April 30, 2007

Neuroblastoma Children's Cancer Society

On behalf of the Board of Trustees at the University of Chicago, I write in appreciation of the Neuroblastoma Children's Cancer Society's gift to benefit the Medical Center. The Society's support means a great deal to our faculty, students, and patients. The Board joins me in sending our gratitude for this generous commitment to Chicago.

James S. Crown, Chairman of the Board, University of Chicago



## NEUROBLASTOMA VIRTUAL TUMOR BANK

### Background

In research of the disease of neuroblastoma, there is much that can be learned from the genetic and biologic study of tumor specimens. At the time of diagnosis, most patients have surgery to remove as much as possible of their tumor. Sometimes it is only possible to obtain a sample of their tumor. Information about the tumor is used to determine how much treatment to give the patient who had the tumor, and also for research to try and find a cure for neuroblastoma. Some tumor cells are placed on slides and then examined by pathologists, and the pathologists either confirm or deny the diagnosis of neuroblastoma. These slides are an important resource for diagnosing the patient as well as for future research. Some slides are stored at the patient's hospital, and with consent of the patient or the patient's parent/guardian, the rest of the slides are sent to a laboratory for storage ("banking") and for future research.

Other tests are run on the tumor sample. In neuroblastoma, certain genes have been found to have abnormalities that are indicative of poor outcome for the patient's fight against the disease. Research has proven that if a patient with neuroblastoma has an abnormality of the *MYCN*, 11q or 1p gene, the patient is more likely to experience a relapse or progression of their cancer, and more likely to die. Patients who have one or more of these genetic abnormalities are usually given more intensive treatment than patients who do not have these abnormalities. Therefore, the genetic test results are very important to the patient's care.

The genetic test results are also important in research efforts to find a cure. With the consent of the patient or the patient's parent/guardian, additional tests are run on the tumor specimen. Sometimes

tests are run on blood and bone marrow specimens too. The results of these tests are used to improve our understanding of why/how neuroblastoma occurs, and how it can be stopped. On the basis of these results, we can design protocols to test improvements and new therapies for the treatment of neuroblastoma.

### The Neuroblastoma Virtual Tumor Bank (NVTB)

An infrastructure was put in place to keep track of specimens after the patient's treatment is completed, and to collect and store data about new biologic or genetic abnormalities that are not currently used to determine a patient's treatment, but that might be used in the future if we had more information about them. The computer database infrastructure is called the Neuroblastoma Virtual Tumor Bank (NVTB), and was founded in 2001. The slides and tumor specimens are physically stored in a locker or freezer, respectively, at a certified laboratory, i.e., the "bank". But the genetic information (data) about the specimens and the research information about the patient are stored in a computer database, the NVTB. This database includes all of the information that is needed to perform research:

- a COG and BPC number that uniquely, yet confidentially, identifies the patient
- dates: diagnosis, study enrollment, relapse or progression, death, last known contact
- genetics: *MYCN*, 11q, 1p, ploidy
- clinical characteristics: age, sex, stage of disease
- type of specimen banked: frozen tumor, slides, blood, bone marrow, DNA
- amount of specimen banked (mg)
- location of banked specimen (which laboratory and which freezer)

- outcome of patient: is the patient still alive? For how long?

These items plus additional information are stored in the NVTB to form a comprehensive database. A key benefit of the NVTB is that regardless of the physical location of the banked specimens, and regardless of which COG study the patient enrolled in, all of the data for neuroblastoma specimens and patients are in one centralized location. This amazing resource permits efficient and comprehensive access to information for use by the research investigators.

### Benefits of the NVTB

For the past six years, the NVTB and those who support it have facilitated global research initiatives in neuroblastoma, serving both COG and non-COG investigators with slides, tumor specimens, and most importantly, the associated data for these specimens. Due to the organization and the proactive approach of the NVTB, the data are of high quality and the items are extremely complete. The NVTB project has a successful track record of providing specimens and data to over 100 research projects during the last six years, resulting in over 60 publications in leading oncology journals.

The NVTB serves as a key resource in other international and large scale projects, such as the International Neuroblastoma Risk Groups (INRG) project, and the Translational Genomics in Neuroblastoma (TGIN) project. INRG is a privately funded cooperative worldwide effort to research consensus on which patient or tumor characteristics are the best ones to uniformly classify patients for comparison of treatments between countries. TGIN is funded in part by the NCI, and will be the largest genomic microarray study ever conducted in any disease.



## METHYLATION OF CASP8, DCR2, AND HIN-1 IN NEUROBLASTOMA IS ASSOCIATED WITH POOR OUTCOME

Letter from Susan L. Cohn, MD, University of Chicago, describing a recently published medical article written by Dr. Cohn, among others. A copy of the complete article is available, upon request, from NCCS.

June 12, 2007

The Neuroblastoma Children's Cancer Society

I have enclosed a reprint of a manuscript we have recently published in a journal entitled, *Clinical Cancer Research* reporting some of our findings in the laboratory. In this study, we investigated epigenetic changes in neuroblastoma cell lines and primary tumor samples. Epigenetic changes can dramatically change the pattern of gene expression and cancer tumor suppressor genes are commonly silenced by this mechanism. We report that methylation of 3 genes is associated with clinically aggressive disease and poor outcome. In addition, we found decreased survival in children with tumors that had a  $\geq 4$  methylated genes. There are several new drugs that are currently being tested in clinical trials that are capable of de-methylating genes. Our studies suggest that this treatment strategy may be effective in neuroblastoma.

We are currently conducting studies that are focused on understanding how and why epigenetic changes occur in neuroblastomas. Learning more about the biology of neuroblastoma will provide insight for the development of new approaches. There are several exciting trials ongoing testing new biologic treatments, including studies with demethylating agents.

This work would not have been possible without your support, and we have acknowledged your support on the 1st page of the manuscript. Thank you for your dedication to finding a cure for this deadly cancer. Please let me know if you would like to visit our new laboratory at the University of Chicago and the new Comer Children's Hospital. I'd be happy to give a tour.

Sincerely,  
Susan L. Cohn, MD  
Section Chief, Clinical Sciences  
Institute for Molecular Pediatric Sciences  
Department of Pediatrics  
University of Chicago

## NEUROBLASTOMA REVIEWED IN MEDICAL JOURNAL "THE LANCET"

Letter from Susan L. Cohn, MD, University of Chicago, describing a recently published medical article written by Dr. Cohn, among others. A copy of the complete article is available, upon request, from NCCS.

July 13, 2007

Neuroblastoma Children's Cancer Society

I have enclosed a recent review paper on neuroblastoma that I co-authored with Drs. John Maris, Rochelle Bagatell, and Mike Hogarty and published in the journal *The Lancet*. In this paper we discuss the enigmatic nature of this pediatric cancer, review the advances in our understanding of the biology of neuroblastoma, and summarize treatment strategies.

We also discuss new approaches to treatment including anti-angiogenic agents. Some of the work on angiogenesis was performed in my research lab and was supported by you. We have acknowledged the support on page 369.

Although we have achieved some success in treating children with high-risk neuroblastoma, more than half of our patients continue to die from disease. I am confident that with further research, we will eventually cure this cancer. Thank you for your continued support.

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



# FUND-RAISERS



**A GIFT OF  
LOVE**

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.



## FRIENDS OF MICHAEL WILLIAMS 6TH ANNUAL GOLF TOURNAMENT

**SATURDAY, SEPTEMBER 22, 2007  
GREEN GARDEN COUNTRY CLUB**

4511 W. Manhattan-Monee Rd, Frankfort, IL 60423 • (815) 469-3350

**Registration begins at 8:30 a.m.**

**Doves fly at 10:00 a.m.**

**Dinner at 4:00 p.m.**

**Foursome \$560 • Individual \$140 • Dinner only \$45**

**Corporate Sponsorship \$5000**

**Beverage Cart \$550**

**Hole/Cart Sponsor \$250**

**Hole-In-One Prizes • Raffle • Golf Awards**

**For sponsorships and golf reservations, call**

**(630) 832-1847 • [www.neuroblastomacancer.org](http://www.neuroblastomacancer.org)**



## 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:**

**Braden Sinclair**

**Tyreke Ambrose**

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

## 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](http://www.neuroblastomacancer.org).

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



# RESOURCES



## 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](http://www.cancer.gov/publications)

## Thank You! Thank You!

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

Timothy Heneghan

David & Mary Jane Jordan

John Michel

Richard Millikin

V. Pappademetriou

Print N More

Thomas & Marjorie Roberts

Peggy Sheehan

Gerald & Donna Smith

Gina Wells

Holly Wright

**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.

## SONGS OF LOVE—THE MEDICINE OF MUSIC

**THE SONGS OF LOVE FOUNDATION CREATES ORIGINAL PERSONALIZED SONGS, FREE OF CHARGE, FOR CHILDREN AND TEENS FACING TOUGH MEDICAL CHALLENGES.**



The Songs of Love Foundation is a 501(c)(3) nonprofit organization dedicated to the memory of Julio Beltzer, a talented singer-songwriter who, just two months before passing away in 1984, wrote and re-

corded a song called "Songs of Love." The comments and letters they receive from children, their families and health care professionals reaffirm the conviction that the songs truly capture each child's spirit and are a wonderful source of comfort, joy and inspiration

to the special people who receive them. Each CD and accompanying lyric is a constant presence, and is always available to be played whenever positive reinforcement is needed.

*"Songs of Love is really what we need to take away our fear"*  
- *Songs of Love*, Julio Beltzer  
(1959-1984)

Contact Information:

Songs of Love Foundation  
P. O. Box 750809  
Forest Hills, NY 11375  
phone 800-960-SONG  
fax 718-441-7372  
email: [info@songslove.org](mailto:info@songslove.org)  
website: [www.songslove.org](http://www.songslove.org)

## RESOURCE SURVIVAL HANDBOOK IS NOW ON-LINE

**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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 Patient's Information  
 Patient's History and Other Important Information  
 Important Phone Numbers  
 Calendars  
 Treatment Journal  
 Children's Memorial Hospital Chicago  
 Family Survey Form

Health Claim Assistance



# OUR SPECIAL CHILDREN



## IN MEMORY OF...

### TYREKE AMBROISE

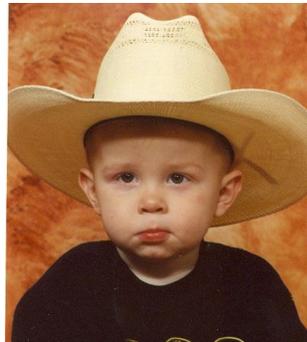
### BRADEN TODD SINCLAIR



I lived in: Florida  
 Family: Mom, Dad, Brother, Sister  
 Favorite place: Home with his family  
 Favorite thing: Kobe, his plush tiger  
 Favorite movie: *High School Musical*  
 Favorite song: *Push It To The Limit* (by Corbin Bleu)

**About Tyreke:** Ricky was a happy, cheerful, caring, sweet little boy. He loved dancing, singing, and being with his siblings.

Late Fall 2005, Ricky who had until been a healthy baby, fell sick. He was diagnosed with stage 4 neuroblastoma in March 2006. Through the long months of chemotherapy, radiation, and bone marrow transplant, he remained a strong little boy. His strength and courage never wavered. The Lord called his angel on June 18, 2007. His body may have left us, but his spirit and memory will endure forever. We love you Ricky!!!



I lived in: Kansas  
 Family: Mommy, Dan, Tya and Emma  
 My favorite place: Outside  
 Pets: Cats  
 Favorite thing: Frogs, flowers and tractors  
 Favorite movie: *Toy Story*

**About Braden:** We would walk in the room and Braden would be making funny faces. He loved picking flowers. Braden was so special to us.

## 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](http://www.neuroblastomacancer.org).

For all donations: My name is \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_