

*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 MEMORY OF...DAVID BRYAN SANTOS*



*State:* New York

*Family:* Marisol, Jose, Stephanie, Serena

*Favorite place:* Legoland in Denmark

*Favorite thing:* Video games

*Favorite movie:* Sonic the Hedgehog

*Favorite song:* "Open the Eyes of My Heart"

*When I grow up, I want to be:*  
Cartoon animator

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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## Board of Directors

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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>

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## 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.



# TREATMENT AND RESEARCH



## UNIVERSITY OF CHICAGO HOSPITAL LETTERS



December 10, 2008

Neuroblastoma Children's Cancer Society

I just wanted to take an opportunity to wish you and your family a happy and healthy holiday season and thank you for your continued support—both financial and moral—of my research. Your partnership has allowed me to advance important neuroblastoma research, and I write to share some exciting publications that highlight my recent collaborative efforts, as a part of the International Neuroblastoma Risk Group (INRG). This 25 country collaboration represents pediatric oncologists treating neuroblastoma in the U.S., Europe, Japan, Canada, and Australia.

Our work has led to the creation of the International Neuroblastoma Risk Group Classification System, with the results published in the December *Journal of Clinical Oncology* articles. This system streamlines the process that oncologists use to identify the stage and aggressiveness of cancer in each patient, and clearly identifies how much treatment each child should receive.

By personalizing treatment in this way, our hope is that children with neuroblastoma will receive the best possible chance of a cure, while keeping the intensity of treatment and its associated side-effects at a minimum.

We are really enthusiastic about this advancement, and continue our other approaches to improve therapies for neuroblastoma patients, in the University of Chicago's uniquely collaborative research environment. When the Knapp Center for Biomedical Discovery opens in the spring of 2009 and our laboratories move to that building, research partnerships will be streamlined. I look forward to showing you that new laboratory space, and in the meantime, I hope you will call me personally if you would like more information about our ongoing laboratory work.

Sincerely,

Susan L. Cohn, MD  
Professor and Director of Pediatric Clinical Sciences



June 4, 2009

Neuroblastoma Children's Cancer Society

Thank you for your continued support in partnership with my neuroblastoma research. I am grateful for my involvement with the Neuroblastoma Children's Cancer Society and for your tireless efforts on behalf of our important neuroblastoma research and the patients whom it benefits.

Enclosed is a copy of a recent *Modern Pathology* publication, which highlights work from our laboratory. In this study, we examined blood vessels and other cells called fibroblasts that comprise part of the support structures (or stroma) in neuroblastoma tumors. It has recently become clear in adult cancers that activated fibroblasts in the tumor stroma commonly secrete proteins that promote tumor growth. Interestingly, we found activated fibroblasts in neuroblastoma cells that were clinically aggressive, whereas very few activated fibroblasts were seen in biologically favorable Schwannian stroma-rich neuroblastoma tumors. These results suggest that it may be possible to modify the behavior of cancers by targeting cells in the tumor stroma that promote tumor growth.

We have acknowledged the Neuroblastoma Children's Cancer Society for its support of this research. Our deeper understanding of the mechanisms regulating this biological process will pave the way for future development of therapeutic strategies for children with aggressive neuroblastoma tumors.

Thank you again for your partnership.

Sincerely,

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

Contact NCCS for copies of both studies.



## CAROLINE PRYCE WALKER CONQUER CHILDHOOD CANCER ACT OF 2008 BECOMES LAW — 110TH CONGRESS 1ST SESSION H.R. 1553

To amend the Public Health Service Act to advance medical research and treatments into pediatric cancers, ensure patients and families have access to the current treatments and information regarding pediatric cancers, establish a population-based national childhood cancer database, and promote public awareness of pediatric cancers.

IN THE HOUSE OF REPRESENTATIVES—MARCH 15, 2007 Ms. PRYCE of Ohio (for herself, Mr. VANHOLLEN, Mr. MCCAUL of Texas, Mr. SESTAK, Mr. FERGUSON, Mr. CASTLE, Mr. YARMUTH, Mr. REICHERT, Mr. HASTINGS of Florida, Mr. SCHIFF, Mr. MICA, Mr. RUPPERSBERGER, Mrs. MUSGRAVE, Mr. LARSEN of Washington, Mr. GRAVES, Mr. PLATTS, Mr. CULBERSON, Mr. ENGEL, Mr. HIGGINS, Mr. BOUCHER, Mr. MORAN of Virginia, Mr. REYES, Mr. KILDEE, Mr. DREIER, Mr. CHANDLER, Mr. SESSIONS, Mr. GRIJALVA, Mr. SHUSTER, Mr. ALGREEN of Texas, and Mr. FORBES) introduced the following bill; which was referred to the Committee on Energy and Commerce.

### A BILL

To amend the Public Health Service Act to advance medical research and treatments into pediatric cancers, ensure patients and families have access to the current treatments and information regarding pediatric cancers, establish a population-based national childhood cancer database, and promote public awareness of pediatric cancers.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, SECTION 1. SHORT TITLE.

This Act may be cited as the “Conquer Childhood Cancer Act of 2007”.

SEC. 2. FINDINGS. Congress makes the following findings:

- (1) Cancer kills more children than any other disease.
- (2) Each year cancer kills more children between 1 and 20 years of age than asthma, diabetes, cystic fibrosis, and AIDS, combined.
- (3) Every year, over 12,500 young people are diagnosed with cancer.
- (4) Each year about 2,300 children and teenagers die from cancer.
- (5) One in every 330 Americans develops cancer before age 20.
- (6) Some forms of childhood cancer have proven to be so resistant that even in spite of the great research strides made, most of those children die. Up to 75 percent of the children with cancer can now be cured.
- (7) Brain tumors are now the most common cause of cancer-related death in children and are the most common solid tumor of childhood. Neuroblastoma is the second most common pediatric solid tumor (after brain tumors) and represents a major therapeutic challenge. More than 50 percent of children with metastatic disease still die despite aggressive, toxic chemotherapy regimens.
- (8) The causes of most childhood cancers are not yet known.
- (9) Childhood cancers are mostly those of the white blood cells (leukemias), brain, bone, the lymphatic system, and tumors of the muscles, kidneys, and nervous system. Each of these behaves differently, but all are characterized by an uncontrolled proliferation of abnormal cells.
- (10) Eighty percent of the children who are diagnosed with cancer have disease which has already spread to distant sites in the body.
- (11) Ninety percent of children with a form of pediatric cancer are treated

at one of the more than 200 Children’s Oncology Group member institutions throughout the United States.

### SEC. 3. PURPOSES.

It is the purpose of this Act to authorize appropriations to

- (1) encourage and expand the support for biomedical research programs of the existing National Cancer Institute-designated multi-center national infrastructure for pediatric cancer research;
- (2) establish a population-based national childhood cancer database (the Children’s Cancer Research Network) to evaluate incidence trends of childhood cancers and to enable the investigations of genetic epidemiology in order to identify causes to aid in development of prevention strategies;
- (3) provide informational services to patients and families affected by childhood cancer;
- (4) support the development, construction and operation of a comprehensive online public information system on childhood cancers and services available to families; and
- (5) establish a fellowship program in pediatric cancer research to foster clinical and translational research career development in pediatric oncologists in the early stages of their career.

### SEC. 4. PEDIATRIC CANCER RESEARCH / AWARENESS.

Subpart 1 of part C of title IV of the Public Health Service Act (42 U.S.C. 285 et seq.) is amended by adding at the end thereof the following:

### SEC. 417E. PEDIATRIC CANCER RESEARCH/AWARENESS

- (a) PEDIATRIC CANCER RESEARCH “(1) SPECIAL PROGRAMS OF RESEARCH EXCELLENCE IN PEDIATRIC CANCERS. (continued on page 5)



## President Signs Landmark Legislation to Increase Federal Investment in Childhood Cancer Research and Awareness

Washington, DC, July 31, 2008 — Washington, DC - Today, the President signed into law H.R. 1553, the Caroline Pryce Walker Conquer Childhood Cancer Act, legislation authored by Congresswoman Deborah Pryce (OH-15) to dramatically increase federal investment in childhood cancer research and awareness. The bill, a historic step in the fight to eradicate pediatric cancer authorizes \$30 million annually over five years to hasten advancements in pediatric cancer research. It creates a national database on childhood cancers to help researchers detect trends in the disease, and provides educational and informational services to patients and families to ensure they have access to appropriate clinical treatment and the array of vital support services.



President George W. Bush is joined at his desk by Hannah Lewis, age 7, left, Wyatt Rech, age 6, Eden Adams, age 8, right, Mrs. Laura Bush, other family members, and Senator Norm Coleman R-MN; Congresswoman Deborah Pryce R-OH; and Congressman Chris Van Hollen D-MD; Tuesday, July 29, 2008, after signing the Caroline Pryce Walker Conquer Childhood Cancer Act of 2008 in the Oval Office of the White House. White House photo by Eric Draper.

dren. Today, brave children around the planet have been provided tremendous hope - a commitment from their government that they will not fight this battle alone."

The scourge of pediatric cancer in our society is overwhelming. Each day 2 classrooms of children in America are diagnosed with cancer, and we lose over 2,000 kids each year to the disease. Of death by disease, cancer is the #1 killer of children under the age of 15. "This bill brings great hope and is truly a catalyst to a cure," adds Co-Founder of Hope Street Kids Randy Walker. "Hope Street Kids along with thousands of families and supporters nationwide leading the fight for their children can stand proud today of their accomplishment. We are especially grateful to Senators Harry Reid D-NV, Norm Coleman R-MN; Congresswoman Deborah Pryce R-OH; and Congressman Chris Van Hollen D-MD; and to the US Congress for all of their hard work to pass this bill. The passage of the Caroline Pryce Walker Conquer Childhood Cancer Act will have a positive impact on children, now and in future generations. With each step, we are moving toward our ultimate goal of a generation free of cancer."

"This is an incredible day for the thousands of children and families who are fighting for their lives against these dreaded diseases," said Pryce. "We may very well look back at this day as the decisive turning point in a war that has caused incalculable pain, suffering and death among our children."

### H.R. 1553

(continued from page 4)

The Director of NIH, acting through the National Cancer Institute, shall establish special programs of research excellence in the area of pediatric cancers. Such programs shall demonstrate a balanced approach to research cause, prognosis, prevention, diagnosis, and treatment of pediatric cancers that foster translation of basic research findings into innovative interventions applied to patients.

#### “(2) FELLOWSHIP OF EXCELLENCE IN PEDIATRIC CANCER RESEARCH.—

(a) The Secretary shall develop a grant mechanism for the establishment, in cooperation with the National Cancer Institute-supported pediatric cancer clinical trial groups, of Research Fellowships in Pediatric Cancer to support adequate numbers of pediatric focused clinical and translational investigators thereby facilitating continuous momentum of research excellence.

#### “(b) NATIONAL CHILDHOOD CANCER REGISTRY.—

The Director of NIH shall award a grant for the operation of a population-based national childhood cancer database, the Childhood Cancer Research Network (CCRN), of the Children’s Oncology Group, in cooperation with the National Cancer Institute. 2

#### “(c) PUBLIC AWARENESS OF PEDIATRIC CANCERS AND AVAILABLE TREATMENTS AND RESEARCH.

The Secretary shall award grants to recognized childhood cancer professional and advocacy organizations for the expansion and widespread implementation of activities to raise public awareness of currently available information, treatment, and research with the intent to ensure access to best available therapies for pediatric cancers.

#### “(d) AUTHORIZATION OF APPROPRIATIONS—

There was authorization of \$30,000,000 for fiscal years 2008 through 2012. Funds appropriated under this section shall remain available until expended.”



# 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](http://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:

**David Bryan Santos**

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



# RESOURCES



## Thank You!

## Thank You!

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

John & Tammy Albomonte

Annmarie Al-Hussainy

Bank of Tokyo-Mitsubishi UFJ

Ann Bishopp

Jessica Black

James & Laurie Deihs

Clara Ferguson

Marshall Gordon

Timothy Heneghan

Highland Chamber of Commerce

Marirose Johnson

Paul Mattes

Monica McKenzie

Daniel McNeil

Donald & Susan Neff

Victor Pierzchalski

Fred & Jeanne Stevens

Pat & Robert Wheeler

## FOCUS ON RESOURCES

### CANCER PATIENTS FLY FREE...

### IN EMPTY SEATS ON CORPORATE JETS

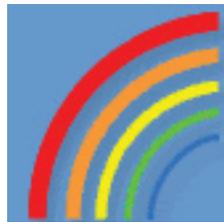


*A message for cancer patients of all ages.* You can fly to recognized treatment centers around the country – *absolutely free* – in the empty seats on corporate jets. No costly airfare. No stressful delays. No unnecessary exposure to airport crowds. **Corporate Angel Network**, a national public charity, 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.

#### TABLE OF CONTENTS

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
Resources and Other Information	Calendars
National Resources	Treatment Journal
Local Resources	Children's Memorial Hospital Chicago
Pamphlets and Books	Family Survey Form
	Health Claim Assistance



# RESOURCES



## NCCS FACEBOOK PAGE IS UP AND RUNNING

<http://www.facebook.com/home.php?ref=home#/group.php?gid=109654430257&ref=ts>



The Neuroblastoma Children's Cancer Society Facebook page is a wonderful resource for families to contact each other. We encourage active participation on this site.

### The Neuroblastoma Children's Cancer Society Organizations - Non-Profit Organizations

The Neuroblastoma Children's Cancer Society is a group made up of volunteers, many of whom have children or relatives who are victims or survivors of this disease. Our organization is an advocate for the children who suffer from neuroblastoma and is dedicated to serving as a support center for their families. The primary focus of the organization is to raise money to assist local research in neuroblastoma cancer, and to raise national awareness to focus additional research and funding until a cure can be found.

Michael James Sexton's courageous effort in his fight against neuroblastoma cancer ended in September 1993 at the age of three. During his nine months of intense treatment, he faced each day with determination, purpose and his smile! "We were shocked by the inability of the medical profession to combat the disease and that no major organization was funding significant

research to promote a front line treatment or cure for neuroblastoma cancer."

"Our family and friends decided to do something meaningful in Michael's memory and in memory of those children who lost their battle with neuroblastoma." Founded in 1994, the Neuroblastoma Children's Cancer Society is a 501(c)(3) non-profit organization dedicated to promoting research and providing support to the children (and their families) diagnosed with neuroblastoma.

"Our organization is dedicated to raising funds for Neuroblastoma research, to change the outcome for all children diagnosed with this disease."

### Our goals

Through our organization, we want to raise funds for research of this disease, to change outcomes, and to stop this disease from taking our children!

For more information about NCCS, see our strategy statement, and a list of our accomplishments.

Website: <http://www.neuroblastomacancer.org>

## 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 \_\_\_\_\_