HOPE for families and friends of children with Neuroblastoma

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 Honor of... Zoey Emerson Coughlin

State: Illinois
My Family: Mommy Keri, brother Landan and sister Tessa
Favorite place: Being outside and being anywhere with mommy
Favorite thing: Her blanket
Favorite movie: Frozen and Dolphin Tales
Favorite song: Let It Go • Do You Want to Build a Snowman
Something special: Zoey is full of life and love. She is such a funny and sweet girl. Zoey is sassy and strong-willed and is going to beat this!!

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!
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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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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.mentalhelp.net/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/
New Approaches to Neuroblastoma Therapy

*Reprinted from New Therapy New Hope website*

**What is neuroblastoma?**

Neuroblastoma (NB) is the second most common solid tumor and the most common extracranial cancer in children. This tumor has a unique biology. Whereas, in some children the tumors can spontaneously regress, in other children with high-risk disease, the cancer is usually metastatic and can become resistant to the best available standard therapy. In approximately one-third of children affected by aggressive neuroblastoma, gene analysis reveals the presence of malfunctioning genes (MYCN, ALK); however, genes that are frequently abnormal have not been identified in the other two-thirds of these children. For this latter group, the tumor cells enlist normal cells in their environment to help them grow, spread, and resist treatments.

**What is NANT?**

The NANT consortium offers hope and resources to patients and their families with relapsed/refractory neuroblastoma when front-line, standard therapy fails. Established in 2000, NANT is the only consortium in the world solely dedicated to developing novel treatments and biomarkers through early clinical trials (Phase I/II) for children whose disease has become resistant to front-line therapies. NANT addresses the most difficult but most relevant question for children with high-risk neuroblastoma: "What is the best strategy to attack this disease when it has escaped all standard front-line therapies?" NANT believes that a comprehensive approach that targets the cancer cells but also their surrounding environment by a team of researchers with converging expertise will make a difference.

Our vision is to develop and test new therapies that target both neuroblastoma cells and normal cells around the tumor and in the immune system to improve the outcome for children with high-risk neuroblastoma with fewer side effects.

**How does NANT work?**

NANT brings together a multidisciplinary team of laboratory and clinical scientists (more than 75) from 14 pediatric hospitals and institutions in the US and Canada (see NANT membership) with complementary expertise in genetics, biology, immunology, chemistry, pathology, biostatistics, clinical investigations, and imaging all with a single focus on finding better treatments for children with high-risk neuroblastoma. Over the last 15 years, NANT has treated more than 600 children affected with neuroblastoma in 23 early phase clinical trials. Currently NANT has 6 open clinical trials (see clinical trials) and plans to open 3 new trials in 2015.

NANT expertise includes detailed pharmacokinetics, biologic correlates, and administration of complex therapies to establish feasibility and safety. NANT investigators have a proven record of moving innovative approaches into standard frontline therapy for high-risk neuroblastoma. Our NANT Biology study established a valuable repository for relapsed and refractory tumor tissue, BM tumor cells, blood, and radiologic images. This unique resource is available to the larger NB research community.

NANT closely interacts and collaborates with the Children's Oncology Group (COG). NANT provides data to COG that are critical for COG to conduct larger Phase II/III randomized trials. NANT has a strong track record of transferring knowledge to COG both for therapeutic and biomarker studies.

A NANT Parent Advisory Committee provides parent input during the development of NANT clinical trials. The Committee includes parent coordinators for education, public website, fundraising, and coordination of local parent representatives.

NANT has created a "Guest Membership" designation to encourage collaboration with non-NANT investigators with innovative ideas for neuroblastoma therapy and with special expertise. Special members may participate as individual investigators, or, if their institution has Phase I capabilities, also enter patients in that selected trial.

**How is NANT supported?**

NANT's support comes from a strong partnership between the government (National Cancer Institute), the pharmaceutical industry, and public philanthropy. Since 2000, the National Cancer Institute has supported NANT through a special grant ($1.2 million/year) which supports fundamental discoveries made in the laboratories of NANT investigators and their translation into innovative clinical trials. Each year, philanthropy and industry provide an essential $1.5 million that make the work of NANT feasible.

What is NANT planning for the future? NANT is proposing a pilot study (NANT-Precision Medicine) to test the feasibility of using a set of specific genetic and cellular biomarkers that could in the future guide the assignment of children with recurrent neuroblastoma to NANT trials that better fit the biology of their tumor. NANT is also planning studies that harness the immune system to attack neuroblastoma cells and new small molecule drugs that target specific malfunctioning genes like MYCN.
Clinical, Biologic, and Prognostic Differences on the Basis of Primary Tumor Site in Neuroblastoma: a Report from the International Neuroblastoma Risk Group Project


**Purpose**

Neuroblastoma (NB) is a heterogeneous tumor arising from sympathetic tissues. The impact of primary tumor site in influencing the heterogeneity of NB remains unclear.

**Patients and Methods**

Children younger than age 21 years diagnosed with NB or ganglioneuroblastoma between 1990 and 2002 and with known primary site were identified from the International Neuroblastoma Risk Group database. Data were compared between sites with respect to clinical and biologic features, as well as event-free survival (EFS) and overall survival (OS).

**Results**

Among 8,369 children, 47% had adrenal tumors. All evaluated clinical and biologic variables differed statistically between primary sites. The features that were >10% discrepant between sites were stage 4 disease, MYCN amplification, elevated ferritin, elevated lactate dehydrogenase, and segmental chromosomal aberrations, all of which were more frequent in adrenal versus nonadrenal tumors (P < .001). Adrenal tumors were more likely than nonadrenal tumors (adjusted odds ratio, 2.09; 95% CI, 1.67 to 2.63; P < .001) and thoracic tumors were less likely than nonthoracic tumors (adjusted odds ratio, 0.20; 95% CI, 0.11 to 0.39; P < .001) to have MYCN amplification after controlling for age, stage, and histologic grade. EFS and OS differed significantly according to the primary site (P < .001 for both comparisons). After controlling for age, MYCN status, and stage, patients with adrenal tumors had higher risk for events (hazard ratio, 1.13 compared with nonadrenal tumors; 95% CI, 1.03 to 1.23; P = .008), and patients with thoracic tumors had lower risk for events (HR, 0.79 compared with nonthoracic; 95% CI, 0.67 to 0.92; P = .003).

**Conclusion**

Clinical and biologic features show important differences by NB primary site, with adrenal and thoracic sites associated with inferior and superior survival, respectively. Future studies will need to investigate the biologic origin of these differences.
NCCS...20 YEARS OF FUND-RAISING AWARDED TO RESEARCH GRANTS

Founded in 1994, the Neuroblastoma Children’s Cancer Society is a 501(c)(3) nonprofit 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. Twenty years later we have raised over $2 million with over 90% awarded to Neuroblastoma research grants which research has helped save children's lives.

In recent years we have funded over $200,000 to the International Neuroblastoma Risk Group database. The database is available to the public if you would like to see this valuable information at http://inrgdb.org/about/. The hope is that with this information about patients, their DNA, and how they respond to treatments, doctors can choose the best treatments and outcome based on genetic profiling for current patients and saving children from ineffective toxic treatments!

SPECIAL THANK YOU TO OUR CONTRIBUTORS

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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.
Forever 9
Softball/Whiffle Ball Tournament and 5K Road Race/Walk
Proceeds to benefit
The Neuroblastoma Children’s Cancer Society

Saturday, August 15, 2015
8AM to 8PM
Pine Bank Park Fields
Main Street, Malden/Melrose Line

On June 26, 2012, Nicholas DeFelice lost his battle to cancer at the age of 9. Forever 9 was started in 2013 as a way to memorialize Nicholas DeFelice. At the age of 3, Nick, was diagnosed with Neuroblastoma. Nick's strength and courage throughout his journey was incredible, he was known to all as Super Nick Power. Nick touched and inspired so many people in his 9 short years. He was an inspiration and HERO to many who knew him. On June 26, 2012, Nicholas DeFelice lost his battle to cancer at the age of 9. The mission of Forever 9 is to memorialize Nick's life by raising funds for organizations that support cancer research.

Come to play, watch, or just enjoy some of the local food. Many of Malden’s favorite food trucks will be there! Try your luck at soaking someone in the dunk tank.

NEW FOR 2015! A 5K Road Race/walk will start at 11 am. For more information, visit: www.forever-9.racewire.com

For more information about the Adult Softball Tournament and the Youth Whiffleball Tournament (Ages 8 – 13), visit our website at https://sites.google.com/site/supernickforever9 where you can download registrations and Register Online!

The proceeds of this year’s event will benefit The Neuroblastoma Children's Cancer Society which is a group made up of volunteers, many of whom have children or relatives who are victims or survivors of this disease. The 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.

https://www.facebook.com/Forever9Tournament
Dr. Susan Cohn,  
University of Chicago  
Chicago, IL

Dear Dr. Cohn:

The 13th Annual 'Friends of Michael Williams' Fund-Raiser is expected to raise close to $20,000. 'Friends of Michael Williams' is a chapter of the Neuroblastoma Children's Cancer Society. NCCS matched the proceeds in the amount of $10,000 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 $30,000! 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,

Jim Sexton  
James F. Sexton  
Chairman

Dori Sexton  
Dori Sexton  
Executive Director
Results of Additional Fund-Raisers

**Operation 214**

To the lovely people of NCCS:

We, the members of the charity group *Operation 214*, would just like to say that we were honored to work with you on such an important cause. This journey has meant so much more to us than a simple class project; it has truly inspired us to continue advocating for the children suffering from neuroblastoma cancer and try to get them the funding they deserve. While our term has come to a close, we wish that we could continue fund-raising to help more. We would like to thank you for the help you provided us, and for coming all the way out to Naperville to meet us at our fund-raiser. It was a pleasure meeting and working with you.

Enclosed you will find the remainder of the money we managed to raise in ten weeks' time, a sum of $442.69, that is a result of our side projects. This number, when added with the total from our fund-raiser at Chipotle on May 15th, amounts to a grand total of $2,371.27. We are excited that you will include this gift in the fall when presenting your grant to the University of Chicago, and we hope that the money can be put to good use in the hopes of finding a cure!

Thank you again for all that you have done for the children and families affected by neuroblastoma. We wish you the best of luck in your future endeavors.

Respectfully yours,

The members of Operation 214

- Harry Bodell
- Elina Khaneeva
- Emily Larsen
- Makayla Pfeiffer
- Crystal Ice

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**Greeley School**

June 1, 2015

The Neuroblastoma Children's Cancer Society  
P. O. Box 957672  
Hoffman Estates, Illinois 60195

Dear NCCS,

These cards were made with love from first through fourth graders at Greeley School. Earlier this spring students chose to help children who are suffering with Neuroblastoma and other pediatric cancers. We implemented a Selfie Challenge (inspired by last year's ALS Ice Bucket Challenge) and raised over $2,300 for your organization.

We hope that your young patients and families will enjoy our words of encouragement and that our donation will help to some day eliminate this horrible disease from our world.

Thanks for all you do!

Mary Jo Ferneding  
Music Director  
Greeley School

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**We Need Your Help!**

NCCS is looking for groups or individuals interested in fund-raising for pediatric cancer. Does your local community have a restaurant that will donate a percentage of sales for a night? Could your community donate a percentage from a group garage sale? We would love to chat about ideas and opportunities to work together towards a cure for our kids! Please feel free to reach us at neuroblastomacancersociety@gmail.com with questions or ideas!
Friends of Michael Williams 13th Annual Golf Outing
Raised Funds for Neuroblastoma Research

September 23, 2014
The Williams Family
Dear Renee and Lou:

It was so wonderful to see you, your family, and all of your friends at the 13th Annual "Friends of Michael Williams" golf outing last weekend. I always look forward to this event and seeing your friends and family. You have done a truly amazing job raising funds for neuroblastoma research, and this organization has played an important role in our ability to improve the outcome of children with neuroblastoma.

I mentioned a number of new treatment initiatives at Comer Children's Hospital, and I have included a brochure for our new I131-MIBG therapy for you to review. MIBG is a molecule that is taken up in neuroblastoma cells, resulting in increased cell kill. I131-MIBG has proven to be one of the most active treatments available in the setting of relapsed neuroblastoma, and we now have an open clinical trial testing I131-MIBG in newly diagnosed high-risk patients. Approximately 50% of high-risk patients can achieve long-term survival rates even higher.

We have also made significant progress with the International Neuroblastoma Risk Group (INRG) Data Base, and we now have data on over 18,000 patients. These data have been made available to investigators around the world, and several seminal studies have been completed and published. We are now poised to link the clinical information collected on these patients with genomic data that has been obtained from their tumors and germline. Once the genomic data are linked, investigators will be able to perform more important research studies that we believe will truly accelerate our understanding of tumor biology and will determine why some children do not respond to current treatments. These data will help us develop more effective treatments, and hopefully ultimately improve survival.

As always, I would be honored to have you visit our hospital and lab and give you a tour. I would also be happy to discuss our research in more detail at any time.

Sincerely,
Susan L. Cohn, MD
Dept. of Pediatrics
Professor & Director
Hematology/Oncology
Clinical Sciences
University of Chicago