HOPE
for families and friends of children with Neuroblastoma

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… Mitchell John Fraser

Family: Laura, John, Katie, Kelsey and twin sister Madison
Favorite place: Home
Favorite thing: Blanket and Soother
Favorite movie: Barney

Something special about: Mitchell was a very happy boy, who, despite his fight with Neuroblastoma, never showed any signs of complaint, at least not verbally, given that he hadn't learned to talk. He took every day as it was given to him. He loved to play, especially with his sisters, and he especially loved Barney.

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!
## TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>OUR SPECIAL CHILDREN</td>
<td></td>
</tr>
<tr>
<td>In Memory of Mitchell John Fraser</td>
<td>1</td>
</tr>
<tr>
<td>Matthew Galvan Runs with the Bulls</td>
<td>8</td>
</tr>
<tr>
<td>TREATMENT AND RESEARCH</td>
<td></td>
</tr>
<tr>
<td>Locoregional MYCN-Amplified Neuroblastoma</td>
<td>3</td>
</tr>
<tr>
<td>Comer’s Children Hospital's CHild Life and Family Education Program</td>
<td>7</td>
</tr>
<tr>
<td>MEMORIAL RUN</td>
<td></td>
</tr>
<tr>
<td>The Neuroblastoma Children’s Cancer Society’s</td>
<td>4</td>
</tr>
<tr>
<td>Michael James Sexton Memorial</td>
<td>8</td>
</tr>
<tr>
<td>&quot;Running With the Bulls&quot; 5k Run/Walk</td>
<td>5</td>
</tr>
<tr>
<td>Thank You to Our 5K Sponsors and Donors</td>
<td>5</td>
</tr>
<tr>
<td>FUND-RAISERS</td>
<td></td>
</tr>
<tr>
<td>10th Annual Michael Williams Golf Outing</td>
<td>6</td>
</tr>
<tr>
<td>Valentine’s Day Toy Drive</td>
<td>7</td>
</tr>
<tr>
<td>Memorial or Honor Gift Request</td>
<td>7</td>
</tr>
<tr>
<td>RESOURCES</td>
<td></td>
</tr>
<tr>
<td>New NCCS Website</td>
<td>3</td>
</tr>
<tr>
<td>Wall of Fame Sponsors</td>
<td>5</td>
</tr>
</tbody>
</table>

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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### GUIDE TO INTERNET CONNECTIONS

- **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/cmweb/default.htm](http://www.childmmc.edu/cmweb/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](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](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)

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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.
Locoregional MYCN-Amplified Neuroblastoma

January 12, 2012

Neuroblastoma Children's Cancer Society
Hoffman Estates, IL

As close partners in my neuroblastoma research efforts at the University of Chicago, you have undoubtedly received many research publications highlighting my work to better understand MYCN-amplification as it relates to poorer outcomes in neuroblastoma. I am delighted to share the enclosed Case Report, which recently appeared in Pediatric Blood Cancer and highlights our work in this area.

The case report highlights our successful treatment of a young patient, whose MYCN-amplified tumor placed her in the Children's Oncology Group's high-risk category. However, given her age and our advanced knowledge of the biology of this disease, we personalized her therapy according to an intermediate-risk protocol. This case highlights the wide range of clinical behavior neuroblastoma tumors have, even those with amplification of this oncogene. Our lab has continued to conduct research to understand the biologic underpinnings of this enigmatic cancer so that we can develop better predictive markers of behavior and more rational treatment strategies.

Your partnership in our research endeavors has real-time impact on patients like the one profiled in this paper. We celebrate her 18 month event-free survival and the role that you played in our ability to successfully personalize our care of her. Please do not hesitate to call me directly if you have any questions about this research. In the meantime, thank you for your support.

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

Contact NCCS for a copy of this study.

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.

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.

New and Improved NCCS Website
Check out our Wall of Fame Heroes

David Bryan Santos
Please update your child's profile on WALL OF FAME http://www.neuroblastomacancer.org
The family pledged that 100 percent of the run proceeds would be earmarked for neuroblastoma research, led by Dr. Susan Cohn at Comer’s Children’s Hospital in Chicago.

Since the start of their Neuroblastoma Children’s Cancer Society in 1994, the Sextons have donated more than $1.5 million into research grants.

Cohn was on hand at the inaugural run, as well as 15-year-old Matt Galvan of Highland, Ind., currently being treated for neuroblastoma at Comer’s Children’s Hospital. Benny the Bull, mascot of the Chicago Bulls, cheered on participants.

Approximately 1,000 children in the U.S. are diagnosed with neuroblastoma each year, it remains one of the worst forms of the children’s cancer.

“Surprisingly,” Sexton said, “the major funders of cancer research have made neuroblastoma a shockingly low priority.”

The run was held on a certified course through the forest preserve Busse Woods on Higgins Road, just west of Arlington Heights Road.

By Eileen Daday; published in the Daily Herald
Thank You! Thank You! To All Our 5K Sponsors and Major Donors

We recognize and give a “big hug” and thank you to our Major 5K Donors. Please support our sponsors.

Dr. Roger and Linda Bielinski
Cathy Carter
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Wall of Fame Sponsors

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

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

My tax deductible contribution is enclosed:

☐ $25,000  ☐ $2,500  ☐ $1,000  ☐ $500  ☐ $100  ☐ Other $______________________________
☐ Research Sponsor  ☐ Child Sponsor  ☐ Honor  ☐ Memory
Child's Name_______________________________________________

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

For all donations: My name is__________________________
Address__________________________ City__________________________ State______ Zip______

Neuroblastoma HOPE
Friends of Michael Williams 10th Annual Golf Outing Raises $25,000 to fund neuroblastoma research

Dr. Susan Cohn,
University of Chicago
Chicago, IL

Dear Dr. Cohn:

The 10th Annual ‘Friends of Michael Williams’ Fund-Raiser raised close to $25,000. ‘Friends of Michael Williams’ is a chapter of the Neuroblastoma Children’s Cancer Society. NCCS matched the proceeds in the amount of $25,000 plus included $5,000 raised from the Michael J. Sexton Memorial "Running with the Bulls" 5K Run.

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 $55,000! We want this to help support the Interactive International Neuroblastoma Information Network directed by Dr. Cohn.

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

Warmest Regards,

James F. Sexton
Chairman

Dori Sexton
Executive Director
February 22, 2012
Neuroblastoma Children's Cancer Society

Dear Dori and NCCS,

The Oncology team of the Child Life and Family Education Program at Comer Children's Hospital would like to sincerely thank you for your generosity this Valentine's Day. We thank you for organizing the donation of teddy bears and gifts for the oncology patients.

Our team of Child Life Specialists focuses on the psychosocial aspects of hospitalization by creating programming to address the emotional, developmental, and educational needs of patients with varying illnesses. The hospital experience is often very challenging for the entire family. It is important for hospitalized children and teens to play and engage in familiar activities as they heal and recover. The holidays in the hospital are often especially challenging. Children are used to receiving special treats at school and home, so through your generous gifts many smiles were made possible in the hospital setting.

We thank you again for organizing this donation. We look forward to continuing our partnership with you in the future. If you ever have questions regarding additional ways to support our oncology program please contact Jenn at 773-702-6485.

Sincerely,

Jenn Loewy, M.S., CCLS
Child Life Specialist II
Hematology/Oncology Specialist

Patricia Manning, Director
Child Life and Family Education

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**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 Honor of:**
Matt Galvan

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

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**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.
Dear Family, Friends, and Sponsors,

Thank you so much for your support and attendance at the Michael James Sexton Memorial "Running with the Bulls" 5K Run/Walk held on September 10, 2011. Thanks to your support and others Michael James Sexton's 21st birthday memorial event and fund-raiser was a huge success! We grossed over $10,000 for our fund-raiser, 100% of the proceeds were presented to Dr. Susan Cohn at our golf outing, "Friends of Michael Williams" on September 24, 2011 for neuroblastoma research in the amount of $55,000.

Besides top runners, Dr. Susan Cohn was awarded a plaque for her dedicated research. Since Michael Sexton's death in 1993, the Neuroblastoma Children's Cancer Society has awarded over $1.5 million to neuroblastoma research. Grand prize winner of the raffle ticket (an NBA autographed basketball by the Chicago Bulls awarded by Bulls Legend Bob Love and Sydney Green) was Matt Galvan, Sr., pulled by his son, 16 year old neuroblastoma patient Matt Galvan Jr. (see picture below left).

Matt Galvan, Jr. started and finished the race with encouragement from Benny the Bull (see picture left). Matt Galvan and many of the thousands of children affected by this disease were winners with the research supported by NCCS over the last 17 years. Michael Sexton started a race where now more neuroblastoma patients can finish - a twenty-first birthday wish come true!

Once again, thank you for your much needed support that is very special to me and my family for this memorable occasion! We are proud to be associated with friends and this community whose support has been overwhelming.

Thank you for "Making a Difference"!

Best regards,

James F. Sexton,
Chairman
Neuroblastoma Children's Cancer Society