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…Kaleo Kana Shadron

State: Oregon
Family: John (Dad), Sandra (Mom), Keanu (brother), Kanoe (sister)
Pets: Chocolate Thunder (Goldfish)
Favorite place: Home
Favorite thing: WWE games on Playstation 2
Favorite movie: Spiderman
Favorite song: Can Touch This

When I grow up, I want to be: WWE Wrestler

Something special about: Kaleo was a 21 year old in a 4 year old body. Nothing could ever upset him. He always had a smile on his face. Kaleo was a strong young man.

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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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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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.

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 organization include public and professional education, patient and family support, and stimulation and support of research — www.histio.org

KIDS WITH CANCER — www.kidswithcancer.com


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 information 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

A newly discovered genetic mutation is more common in teens and young adults than in infants with a nerve tissue cancer called neuroblastoma.

The gene with the defect is called ATRX. While this defect was found in many teens and young adults with neuroblastoma, none of the infants with the disease who were tested had this genetic defect. This is important because babies are the ones who most commonly develop neuroblastoma. And, in babies, the disease tends to take a much less aggressive course.

"In infants, neuroblastoma is often treatable. In older patients, it tends to be more clinically aggressive," said study co-author Dr. Alberto Pappo, director of the solid tumor division at St. Jude Children's Research Hospital in Memphis, Tenn.

"About 90 percent of neuroblastomas happen in children less than 10 years old. When it happens in teens and young adults, they usually tend to have poorer clinical outcomes. They relapse over and over again. They can survive for many years with the disease, but they ultimately die of the disease," Pappo noted.

The discovery of the mutation in the ATRX gene is an "exciting but preliminary finding. We still need to try to determine if this mutation is associated with any significant differences in survival," added Pappo.

Results of the study are published in the March 14 issue of the Journal of the American Medical Association.

Overall survival rates for neuroblastoma are 88 percent for babies under 18 months at the time of diagnosis, 49 percent in children between 18 months and 12 years, and just 10 percent in teens and young adults who are diagnosed with the disease, according to background information in the study.

Because the disease takes such a different course depending on a patient's age, researchers have long suspected that there are likely different subsets of neuroblastoma, and that different genetic mutations may account for the differences in prognosis by age.

To see if there were any identifiable differences, the researchers conducted what's known as whole genome analysis on tumor samples from 40 infants, children and young adults with advanced neuroblastoma. The researchers then looked to see if there were any similarities.

The investigators found that mutations in the ATRX gene were present in 100 percent of teens and young adults. Just 17 percent of children under age 12 had this same mutation, and none of the infants tested had it.

To confirm these findings, the researchers tested tumor samples from an additional 64 people who had advanced neuroblastoma and found that the ATRX mutation was identified in 33 percent of adolescents and young adults and 16 percent of the children under age 12. Again, no evidence of this mutation was found in infants with the disease.

When the two groups were combined, the ATRX mutation was present in 44 percent of teens and young adults and 17 percent of children.

Pappo said finding will likely spur more research, and could potentially be used to develop a screening test to determine who might have more (or less) aggressive cancer. And, eventually, there's a possibility that by reprogramming the ATRX gene, doctors could alter the cancer cells. But, he cautioned that the study's findings are preliminary and any practical uses are a long way off.

Commenting on the study, Marc Symons, an investigator at the Center for Oncology and Cell Biology at the Feinstein Institute for Medical Research in Manhasset, N.Y., noted that "most cancers are not thought of as being a single disease, and it's important to characterize the subclasses."

And, Symons added, "This is a preliminary study that highlights their discovery of the ATRX mutation in a specific population. It opens the way to potential new therapeutic targets," explained Symons, but fixing this type of genetic mutation is very challenging, he explained.

Dr. Rosanna Ricafort, director of the pediatric stem cell transplant program in the division of pediatric hematology/oncology at the Children's Hospital at Montefiore in New York City, agreed that the findings are preliminary. "This is an interesting study, but more and larger studies need to be done before we'll have the ability to translate what's been learned into improving diagnosis and directing therapies."

The most important factor, she said, is knowing whether people who have this mutation have more or less aggressive cancer. "This study has identified the mutation, but doesn't correlate it with outcome," she added.

This isn't the first study to link genetic similarities in neuroblastomas. Another study, reported in 2009 in the journal Nature, compared the genes of people with and without neuroblastomas and found that a specific "copy number variation" -- a kind of genetic trait -- doubles the risk of a child developing the disease.

More Information--Learn more about neuroblastoma from the U.S. National Cancer Institute.

SOURCES: Alberto Pappo, M.D., director solid tumor division, St. Jude Children's Research Hospital, Memphis, TN; Marc Symons, Ph.D., investigator, Center for Oncology and Cell Biology, Feinstein Institute for Medical Research, Manhasset, NY; Rosanna Ricafort, M.D., director, pediatric stem cell transplant program, division of pediatric hematology/oncology, Children's Hospital at Montefiore, NYC; March 14, 2012, Journal of the American Medical Association.
The Neuroblastoma Children’s Cancer Society partnering with The 16th Annual Chicago Half Marathon and 5K on September 9, 2012

Please join and support our team "Running with the Bulls" Pediatric Cancer Team

**All Runners:** register online only at http://www.chicagohalfmarathon.com, enter charity team code CHRNCC12 to join our team NCCS "Running with the Bulls" Pediatric Cancer Team. In addition, fill in the information below and return by mail or fax, along with team t-shirt size for "Running with the Bulls" Pediatric Cancer Team. Team discount by August 9, 2012 and registration reimbursement for all runners who receive $250 or more in sponsorship!

Yes! I want to help The Neuroblastoma Children's Cancer Society fund research for new treatments in the fight against neuroblastoma and provide support for patients and their families.

- Runner Sponsor  $___________
  - General: $250 per runner
  - Name of Runner(s) ______________________________
  - T-shirt:  S  M  L  XL  XXL

- Team Sponsor  $___________
  - Sponsors for $500, $1,000, or $2,500 will be recognized in press release/t-shirts

- I would like to make a tax deductible contribution  $___________

**TOTAL**  $___________

**For All (circle one):**  **Supporter**  **Runner**  **Volunteer**

My name is ____________________________________________

Address ____________________________________________

City ____________________________________________ State ____________ Zip ____________

Email ____________________________________________ Telephone ( ________)

**Volunteers (circle one):**  **Day of Race**  **Fundraising**  **Runner 2013**  **Other___________

Please join our team in memory of Michael James Sexton and in honor of Matt Galvan and all the children affected by Neuroblastoma cancer!

The Neuroblastoma Children's Cancer Society  •  P.O. Box 957672  •  Hoffman Estates, IL 60195  •  (847) 605-0700  •  Fax (847) 605-0705

www.neuroblastomacancer.org—check out our Wall of Fame Heroes for whom we are running
Friends of Michael Williams
cordially invites you to
The 11th Annual Golf Outing
Saturday, September 22, 2012
Glenwoodie Golf Course
19301 South State Street, Glenwood, IL • (708) 758-1212

Registration begins at 8:30 a.m. • Doves fly at 10:00 a.m. • Dinner at 4:00 p.m.

Kindly RSVP as soon as possible (reservations on a first come/first served basis)

Proceeds to Benefit The Neuroblastoma Children's Cancer Society
An advocate for stricken children and their families, the primary focus of this Society is to raise money to assist research in Neuroblastoma. The Society hopes to bring the fight to a national level to increase funding for additional research for a cure. Friends of Michael Williams supports this effort.

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Hole-in-One Prizes
Raffle
Golf Awards

Yes, I want to help The Neuroblastoma Children's Cancer Society fund research for new treatments in the fight against neuroblastoma and provide support for patients and their families.

My tax-deductible contribution is enclosed.

_____ General Donation $__________

_____ Golf only ($140 per golfer) $__________

_____ Dinner only - 4:00 p.m. $__________
$45 per person: # of guests _______

_____ Raffle Tickets $__________
$5 each, 5 for $20, and 30 for $100
Raffle Ticket order needs to be received by date of the event

TOTAL $__________

For All Donations:
My name is ____________________________

Address ______________________________

City __________________________ State ______ Zip ______

NCCS, Friends of Michael Williams
c/o Beth and Hank Possley
599 Berkley Avenue
Elmhurst, IL 60126
(630) 832-1847

Neuroblastoma HOPE Page 5 • Summer 2012
A Small Change to the Tax Code will send More Money to Research on Childhood Cancer

At 8:30 p.m. on a Wednesday night, after seeing patients all day, John Cunningham, MD, left the University of Chicago Medicine campus to drive 200 miles to Springfield. He was on a mission: to be ready first thing in the morning to testify before the House Revenue and Finance Committee for a small change to the state tax code that could make a big impact on childhood cancer research.

"The scientists in Illinois who focus on pediatric cancers know that we can develop better and smarter therapies, if we have the appropriate resources," Cunningham told the legislators in their early-morning session. He directs the largest pediatric cancer research program in the state.

The proposal before the Committee was for a small addition to state income tax forms. The change would allow people to donate part of their tax return money to a new Childhood Cancer Research Fund. Research institutions like the University of Chicago could apply every year for research money from this fund. According to the bill, the fund would advance the "early detection, prevention, cure, screening, and treatment of childhood cancer, and may include clinical trials."

"We need better and smarter therapies," Cunningham said. He directs the Center for Childhood Cancer and Blood Diseases at the University of Chicago, where he and other researchers treat many children with cancer every year. They also investigate new therapies and run clinical trials of developing drugs and treatments.

The advances of the past 60 years in cancer research have brought the cure rate for children up to 70%. But their treatments come at a great cost.

Many young cancer survivors still bear the stigma of chemotherapy, radiation therapy, and the many other treatments that we currently use against cancer." Filling young bodies with cytotoxics to cure cancer can have long-term side effects, including infertility, heart failure, or secondary cancers. The University of Chicago program is working on approaches to reduce these unwanted long-term toxicities.

Cunningham reminded the group of Illinois' rich heritage of scientific breakthroughs in cancer research."This was the state where the molecular basis of cancer was discovered, through the work of Janet Rowley. Our institution lead the research that resulted in successful bone marrow transplants." he said.

He also highlighted more recent advances made by his colleagues throughout Illinois. "Stewart Goldman's work at Children's Memorial Hospital is pushing the frontiers for using experimental drugs for brain tumors," he said. The work of the University of Chicago scientists has led to new treatment protocols for neuroblastoma and breakthroughs in stem cell transplant.

Children aren't the only beneficiaries of research on childhood cancers. Cunningham said, "There is a new protocol for treating acute lymphoblastic leukemia in adults, based on our research in children at the University of Chicago. We are hopeful that it will improve the cure rate for the disease in all affected individuals."

The physician was joined at the hearing by four-year-old Atia Lutarewych, (continued on page 7)
RESEARCH & RESOURCES

Tax Code Change
(continued from page 6)

who was diagnosed with acute lymphoblastic leukemia three years ago. Cunningham and the pediatric cancer team at Comer Children’s Hospital helped induce a remission of Atia's leukemia.

Atia’s mother Laura Lutarewych, also a cancer survivor, told the state representatives about her family’s experiences having a child with cancer. She said that watching her daughter endure toxic treatments often made her wish they could swap places, so that she could take away her child's suffering.

"Ironically, if a parent could swap places with their child, they would have access to more resources and more extensively funded research," Laura Lutarewych said. With only 4% of the national cancer research budget going to childhood cancers, she argued, our country has wrongfully devalued the lives of children.

Taxpayers can donate to various charities through the income tax checkoff program in Illinois, like military family relief, child abuse prevention, and assistance to the homeless. A dozen organizations shared about $1.3 million in 2010. Organizations that don't pull in $100,000 are bumped off the list.

The proposal to add the Childhood Cancer Research Fund to the list of income checkoffs was met with great enthusiasm by the Revenue and Finance Committee. The chair recommended that it be added to the tax code for the next year.

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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 Memory of:
Lauren Brown

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.
Dear Ann, Emily, & Taylor,

Thank you very much for running resulting in donations over $9,000 in memory of Lauren Brown. An acknowledgement has been sent to the families. We have received an outpouring of love and support for your run of the Chicago Half Marathon run on September 11, 2011.

Thanks to your support and others, 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.

Matt Galvan, Jr., a 16-year-old neuroblastoma patient started and finished our 5K race on September 10, 2011 with encouragement from Benny the Bull. Matt Galvan and many of the thousands of children affected by the disease were winners with the research supported by NCCS over the last 17 years. Lauren inspired you to run a race so more neuroblastoma patients can finish thanks to your awesome support!

It is in memory of Lauren, Michael, and in honor of our children that we continue the battle for a cure!

Once again, thank you for your much needed support,
Best Regards,
James F. Sexton, Chairman
Neuroblastoma Children's Cancer Society

Dear Family & Friends,

Seventeen years ago we lost our precious daughter/sister, Lauren. Lauren was a very sweet and joyful little girl and our family misses her very much. Lauren was diagnosed with stage IV Neuroblastoma in 1992 and passed away in 1994.

Neuroblastoma is an aggressive pediatric cancer. There are between 500-1000 new cases each year. Neuroblastoma is responsible for 50% of pediatric cancer deaths. There have been advances since Lauren's death. However, the cure rate for stage IV NB is still less than 30%. That is a great improvement from when Lauren was diagnosed, but it isn't good enough.

To honor Lauren and to help find a cure for children diagnosed with stage IV Neuroblastoma, we will be participating in the Chicago Half Marathon on September 9th. We would greatly appreciate your prayers and support.

If you would like to make a donation please send your check to The Neuroblastoma Children's Cancer Society, In Memory of Lauren Brown, P. O. Box 957672, Hoffman Estates, IL 60195.

The funds that are raised will be included in a grant for Dr. Cohn (Lauren's Oncologist) at the University of Chicago Hospital, which supports an international database of all NB patients. Please keep us in your prayers.

We will be wearing purple (Lauren's favorite color) as we push to accomplish our goal of crossing the finish line on our own two feet! We appreciate your support as we remember our beloved Lauren.

Ann, Emily, & Taylor

If you would like to make a donation please send your check to The Neuroblastoma Children's Cancer Society, In Memory of Lauren Brown, P. O. Box 957672, Hoffman Estates, IL 60195.

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Ann, Emily, & Taylor

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_________

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Neuroblastoma HOPE