



Vol. 11, No. 2
Spring 2007

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

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... TYLER ANDREW LUEDTKE

***I lived in:** Washington*

***Family:** Mom Heidi and Dad Brian Luedtke*

***Pets:** Two dogs; one cat*

***Favorite place:** Chuck E Cheese; Ronald McDonald House, Seattle*

***Favorite thing:** Pooh blankie; his kitty Sarah*

***Favorite movie:** Spiderman*

***Favorite song:** Three Doors Down - Kryptonite*

About Tyler: Tyler managed to touch more peoples' lives in his five years than most people are able to do in a lifetime. His courage and determination inspired countless people. Tyler was a very loving and affectionate boy. He loved playing with his friends and having sleepover parties. He was very creative and an amazing artist. He loved music, drawing, riding his skateboard, and playing dress-up in his superhero costumes. Tyler lived every day to the very fullest, and was an inspiration to all who knew him.

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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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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THANK YOU!**



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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

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

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/

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

INFORMATIONAL SITES ON THE INTERNET: www.acor.org;



SPARC ENHANCES TUMOR STROMA FORMATION AND PREVENTS FIBROBLAST ACTIVATION

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.

February 1, 2007

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

Dear NCCS:

I have enclosed the first of several papers that will be published in the next few months reporting some of the results of our research studies.

In the paper enclosed with this letter, we used a novel tumor model to further study an extracellular matrix protein called SPARC. As you may recall, we have previously reported that SPARC is expressed in neuroblastoma tumors that are associated with a more favorable prognosis and have shown that this protein can block blood vessel formation or angiogenesis. We have also shown that SPARC is capable of inhibiting the growth of neuroblastoma tumors in mice.

In this study, we have shown that SPARC can also modify other tissues in the tumor stroma. The stroma is comprised of all the tissues in the tumor that are not malignant. Fibroblasts are commonly found in the stroma of cancers, and in general these cells are modified or activated by signals from the cancer cells. When the fibroblasts are activated, they produce a number of signals that stimulate angiogenesis and promote tumor growth. In this study, we show that SPARC can block the activation of fibroblasts in tumors.

It is now well recognized that the tissues in the tumor stroma can influence the growth of malignant tumors. Interestingly, "normal" stromal tissue provides cues that constrain the growth of neoplastic cells. Cancer cells can induce changes in the stroma that will lead to conditions that will actively support tumor progression. Thus, agents that will promote the assembly of "normal" stroma may prove to be effective in inhibiting tumor growth. Our studies indicate that SPARC may be a novel therapeutic candidate for treating neuroblastoma and other cancers, and we are in the process of developing small SPARC peptide mimetics to test this hypothesis.

We would not have been able to perform these studies without your generous support, and we have acknowledged your support on page 9. I would be happy to talk to you further about these and other studies ongoing in the lab.

If you would like to visit me at my new location at the University of Chicago, I would be happy to give you a tour of our laboratory and the new Comer Children's Hospital. In addition to my recent recruitment, a dynamic new Chief of the Section of Pediatric Hematology/Oncology named John Cunningham has recently been hired. John is a transplantologist who has worked for the past 15 years at St. Jude Children's Research Hospital. We are excited about building a premier program at the University of Chicago for children with blood and cancer disorders. Being able to develop novel therapeutics for children who fail conventional cancer therapies will be an integral part of our mission.

Sincerely,

Susan L. Cohn, MD
Professor and Section Chief
Institute for Molecular Sciences
Department of Pediatrics
University of Chicago

\$\$

FUNDRAISERS

\$\$

NCCS DONATED VALENTINE'S DAY GIFTS FOR ONCOLOGY PATIENTS AT COMER CHILDREN'S HOSPITAL

C O M E R
CHILDREN'S
HOSPITAL



THE UNIVERSITY OF
CHICAGO

February 14, 2007

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

Dear NCCS:

The Child Life Program at Comer Children's Hospital would like to thank you for your donation of Valentine's Day Gifts for the oncology patients. As the hospital continues to grow and expand, so do the numbers of children and families we serve. It can be difficult for patients to spend holidays in the hospital and/or in the day treatment room

clinic receiving chemotherapy. Your thoughtfulness and generosity is extremely helpful in bringing a few smiles to these patients during this Valentine's Day.

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. Because of your support, this Valentine's Day they will have additional toys, projects and games to brighten up their day. One teen girl loves to distract herself when in the hospital by making bead bracelets. A smile, extended from ear to ear, upon receiving a bead kit donated by your group. Another young girl received a stuffed animal and drawing pad...these items were carried around with her all day long.

We would like to thank you for your contribution. We look forward to continuing our partnership with you in the future. If you ever have questions regarding additional ways to support our program, please contact Jenn at 773-702-6485.

Sincerely,

Jenn Krieger,
Child Life Specialist II
Oncology Specialist

Pat Manning
Director
Child Life and Family Education

Thank You! Thank You!

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

V 3 Companies

Robert Berman

Northeast Region QCUSA
(Audi Quattro Club USA)

Marshall Gordon

Jim & Barbara O'Toole

M & E Herres

Annmarie Coughlin

Kirk Taylor

Robert & Pat Wheeler

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Bruce Weiner

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Morton & Evelyn Golden

Marsha & Gerald Feldman

Karlene Loranz

Colleen Hehli

Margaret Haugh

Randell White

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E&S Rosensweig



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.

IN HONOR 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:

Sharon Winquist-Horonzy

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

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.

NATIONAL CANCER INSTITUTE

CANCER INFORMATION SERVICE

1-800-4-CANCER (1-800-422-6237)

- Options: Tips to prevent cancer, Informational Materials, Answers to questions about cancer, Other Resources

www.cancer.gov/publications

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.

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



RESOURCES



KIMBERLY-CLARK CHILD'S FACE MASK FEATURING DISNEY CHARACTERS

January 5, 2007

Neuroblastoma Children's Cancer Society
PO Box 957672
Hoffman Estates, IL 60195

To Whom It May Concern:

We have heard from many parents who have been looking for a facial protection solution for their child and until now, had only an adult mask to choose from. Because we sell our child's face mask mainly through healthcare distributors, we do not advertise directly to consumers. However, after hearing from so many parents who said they had difficulty finding out about our child's mask and then further difficulty finding a way to buy them, we decided to try to spread the word through organizations such as yours that are in direct contact with parents. Here is what one parent had to say:

"Sam has the immune system of a tiny baby. He is allowed in our front yard and backyard, but that's basically it. Several weeks ago, I was searching for little masks as Sam was going back and forth to radiation twice a day and couldn't keep the big mask on. It was not serving any purpose. I looked all over the country and couldn't find a thing. Now, Sam uses your masks weekly as he ventures out to his oncology appointment. I want to personally thank the ingenious people at Kimberly-Clark for creating masks for little kids. It's the greatest thing." Dana Eisenberg

Kimberly-Clark is the first company to have designed a mask specifically to fit small faces, understanding that adult masks cannot provide the fit, comfort and protection children need. And now that our mask features Disney characters, getting kids to wear them is easier. Illnesses that most people shake off in a few days can become life-threatening for immunocompromised children. That's why it's especially important that children who are undergoing treatment related to cancer, transplants, or other immunosuppressive conditions wear a mask when visiting their physician or in other situations that may put them at risk of acquiring a respiratory infection.

For your convenience, I have enclosed a sample along with some informational material. Feel free to contact me if you are in need of additional samples or would like assistance in communicating product information to your constituents in some other way. More information is also available at our website at www.kchealthcare.com/childmask or by calling 1-800-KCHELPS.

Regards,

Corinne Knoblach
Product Manager
cknoblach@kcc.com



RESOURCES



RESOURCE SURVIVAL HANDBOOK IS NOW AVAILABLE 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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Chapter 3b	Local Resources	Chapter 4e*	Children's Memorial Hospital (Chicago)
Chapter 3c	Pamphlets and Books	Chapter 5*	Family Survey Form
Chapter 3d	Health Claim Assistance		

* Still in process

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 _____



OUR SPECIAL CHILDREN



IN HONOR OF...

DILLION JOSEPH NEVELS

TRAVIS STONE McWILLIAMS



I live in: Mississippi

When I grow up, I want to be:
a scientist

My family: Steve & Christie Taylor,
parents; Shane Emrick, brother.

My pet: Fish

My favorite place: Arcade

My favorite thing: Video Games

My favorite movie: *Showlen Showdown*

My favorite song: *Not What You See* (by Kutluss)

About Dillion: Dillion was diagnosed when he was 18 months old and was in total remission by the time he was 24 months old. He is now 10 years old and is doing great. In November 2006 we made our 5th year of remission and was told we are still free. I would like to take this time to let some of you know that no matter what the doctors say, the Lord our Jesus Christ is the only one with the true answers.

I live in: Utah

When I grow up, I want to be: a Rock Star

My family: Five in family; Mom, Dad, Travis, Nicole, Dusty

My favorite place: Aunty

My pets: Eyore (dog); Suzy & Rosie (cats); Brandy & Buck (horses)

My favorite thing: Swords

My favorite movie: *Blues Clues*

My favorite song: The song off of Cyue

About Travis: Travis is a 12-year-old young man that was born with neuroblastoma. Although he is well behind his age (due to medication, etc), he is a wonderful little boy. He has come so far, it is a miracle. He just had surgery last year again and to look at him you would never know. It is just amazing how all these children do it. Travis loves life and everyone in it. Travis is in the Special Olympics and attends as many sports he can. He just wants to be like all the other kids and and does his best at everything.

ILA JEAN RATHBONE

COLE JAKOB HINKEL

I live in: New York

My family: Parents John & Jennifer; brother Howie (6); Sister Monica (5)

My pets: Cubby (dog)

My favorite thing: Elmo

My favorite song: *ABC song*

About Ila Jean: Ila Jean is the most amazing little girl. She has fought so courageously at such a young age. She will win this battle and become proof that miracles do happen.

I live in: Inidana

My family: Mom, Dad, big brothers Austin and Brayden

My pets: Sheltie Stormy

My favorite movie: *Mickey Mouse Clubhouse*

About Cole: Cole is a very beautiful baby boy. We love him very much and have support and prayers for him coming in from all over!!

DECLAN ELMER-THERRON WILLIAMS

I live in: Florida

My family: Mom Tereasa; Dad Charles; many other relatives

My favorite place: Home

My favorite thing: Piano

My favorite movie: *Clifford*

My favorite song: *Pat A Cake*

About Declan: Declan is a very sweet and happy little boy that melts your heart when he smiles at you.