**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... Kayleigh Nevaeh Justice**

- **State:** Ohio
- **Family:** Valerie (mother), Lance (father), Alden Holbrook (brother), Izabella Holbrook (sister), Lisa Chan (NeeNee)
- **Favorite place:** NeeNee
- **Favorite thing:** Little pet shop toys
- **Favorite movie:** *Harry and the Hendersons*

**Something special:** Kayleigh is a very special girl who enjoys lots of things from swimming, camping, ballet, and tap dancing, to playing with her brother and sister and spending time with her family. She is very sweet and has a very kind heart. She thinks about how other people might be feeling, even if she isn’t feeling all that great herself. She will do amazing things with her life, I’m sure of it.

http://www.youtube.com/watch?feature=player_embedded&v=lNG5WtNonX0

http://www.neuroblastomacancer.org/photos/7254.jpg

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.

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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.ucchicagochildrens.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://neuroblastomacancer.org

**CHILDREN’S ONCOLOGY GROUP:** http://www.childrensoncologygroup.org

**INFORMATIONAL SITES ON THE INTERNET:** http://www.cdc.gov/cancer/
Using Germline Genomics to Individualize Pediatric Cancer Treatments

An excerpt by Susan L. Cohn, M.D. among others in the Clinical Cancer Res. May 15, 2012; 18(10); 2791-2800.

Abstract

The amazing successes in cure rates for children with cancer over the last century have come in large part from identifying clinical, genetic and molecular variables associated with response to therapy in large prospective clinical trials and stratifying therapies according to the predicted risk of relapse. There is an expanding interest in identifying germline genomic variants, as opposed to genetic variants within the tumor, that are associated with susceptibility to toxicity and for risk of relapse. This review highlights the most important germline pharmacogenetic and pharmacogenomic studies in pediatric oncology. Incorporation of germline genomics into risk-adapted therapies will likely lead to safer and more effective treatments for children with cancer.

Introduction

The majority of children with cancer receive treatment that is tailored according to their predicted risk of relapse, based on a combination of clinical features, peripheral blood markers, and tumor genetics. This approach has led to significant improvement in the outcome of patients with a broad range of pediatric cancers. However, within risk-groups, it remains difficult to predict which child is at greatest risk of experiencing chemotherapy-related toxicities and/or non-response. Pharmacogenomics is the study of the genetic basis for individual differences in drug efficacy and/or toxicity with the goal of identifying patients at risk for severe toxicity and/or non-response prior to the initiation of therapy. Although the routine use of pharmacogenetic or genomic testing is not done at most pediatric oncology centers, recent studies have demonstrated that germline genetic biomarkers can be used to personalize therapy and improve the overall care of children with cancer. In this review, we will provide an overview of the clinical and preclinical studies aimed at identifying genomic markers for risk of toxicity of non-response in pediatric cancers; describe the results of genome-wide studies; and discuss how these findings can be implemented into improved care for pediatric cancer patients.

Conclusions and Future Directions

The studies outlined in this review highlight the significance of germline genonomic variation in both susceptibility to toxicity and response to therapy. To date, only small numbers of clinically relevant, germline genetic biomarkers have been identified in children with cancer. Based on the available data, larger prospective clinical trials of pharmacogenetic-based dosing of thiopurines and irinotecan are warranted to optimize the maximum effective dose of these agents based on TPMT and UGT1A1 genotype, respectively. With minimal comorbid conditions, the pediatric population offers an ideal setting to study pharmacogenomics of anticancer agents. Most children diagnosed with cancer in the developed world are entered into collaborative clinical trials, and the rise of both tumor and germline biobanking will ensure that materials are available for future pharmacogenomic investigations. Given the models odds ratios of most genome wide associations and the rarity of pediatric malignancies, international collaboration for future GWAS will likely be necessary.

Recent advances in our knowledge of the fundamental genomic alterations that are associated with varying tumor behavior and patient outcome has led to more precise prognostication and improved treatment stratification. Significant progress has also been made in the identification of specific molecular targets for novel therapeutics in some pediatric malignancies (reviewed in this edition of Clinical Cancer Research). To achieve our long-term goal of developing more effective, individualized therapy for all children with cancer, it will be important to define additional key pathways in pediatric tumors that can be exploited therapeutically. In addition, we need to improve our understanding of the heritable genetic factors that contribute to the response and toxicity to chemotherapeutic agents in children.
Caroline Pryce Walker Conquer Childhood Cancer Reauthorization Act H.S.2607/S.1251

Research Expansion

The Caroline Pryce Walker Conquer Childhood Cancer Reauthorization Act is bipartisan legislation that would expand the research of childhood cancers, improve efforts to identify and track childhood cancer incidences, and identify opportunities to expand the development of drugs necessary to treat the 13,500 children diagnosed with cancer in the U.S. every year.

The Children’s Cause, working with Congress since late 2012, helped sponsors and colleagues understand the importance of reauthorizing the Caroline Pryce Walker law. The bill was endorsed by 19 organizational members of the Alliance for Childhood Cancer and the 150 childhood cancer advocates discussed this bill with their senators and representatives during the 2013 Childhood Cancer Action Days.

The Caroline Pryce Walker Conquer Childhood Cancer Act of 2008 passed unanimously in the House and Senate and was signed into law by President Bush five years ago. This reauthorization would build upon, expand, and improve the law’s efforts for childhood cancer and continue the federal government’s commitment to improving the future for children with cancer.

Expanding Opportunities for Childhood Cancer Research

Due to the relatively small population of children with cancer and the geographic distance between these children, researching childhood cancer is incredibly difficult. No single hospital or cancer center treats enough children with a specific cancer type to conduct the research necessary to identify cures for all of these diseases.

The Caroline Pryce Walker Conquer Childhood Cancer Reauthorization Act would authorize NCI to establish childhood cancer biorepositories to help overcome of these research barriers. The biorepositories would build on existing efforts to collect specimens for childhood cancer patients enrolled in NCI-sponsored clinical trials to collect and maintain relevant clinical, biological and demographic information on all children with cancer. This information would be made available to health care professionals and scientific researchers.

Improve Childhood Cancer Surveillance

Building upon efforts of the last five years, this bill would authorize grants for state cancer registries to identify and track incidences of child adolescent, and young adult cancers.

Identifying Barriers to Childhood Cancer Drug Development

While advances in adult oncologic drug development have been made in recent years, very few drugs have been approved to treat children with cancer. The bill would initiate a GAO study to investigate the feasibility of expanding requirements for pediatric studies of adult oncologic drugs and made recommendations for overcoming barriers that currently exist.

Survivorship

Childhood Cancer Survivors’ Quality of Life Act (H.R.2058)—This legislation would improve childhood cancer survivors’ care, research, and treatment. Specifically, it would create pilot programs to evaluate model systems of care for survivors; support research to identify and track late effects of childhood cancer treatments; establish long-term survivor-ship clinics; and emphasize the psychosocial needs of survivors.

Evaluating Models of Care

The bill would create pilot programs to explore models of care to find the most effective ways to provide follow-up care to childhood cancer survivors. In addition, it would promote the development of initiatives to improve care coordination and the effective transition of care between providers.

Improving Access to Care

The bill authorizes grants for research on late effects and follow-up care for childhood cancer survivors, including the prevalence and etiology of late effects of cancer and its treatment, including physical, neurocognitive, and psychosocial late effects, risk factors associated with late effects of childhood cancer, and barriers to follow-up care that childhood cancer survivors face within minority and medically under served communities.

Clinics for Long-Term Follow-Up Services

The bill authorizes to eligible medical schools, children’s hospitals, and cancer centers to establish and operate clinics for comprehensive, long-term, follow-up services for pediatric cancer survivors.

Workforce Development Collaborative on Psychosocial Care

The bill would convene a workforce of cross-specialty, multi-disciplinary educators, advocates, and providers to develop workforce competencies in relevant psychosocial services, curricula for continuing education, and strengthen the emphasis on psychosocial care.
**Friends of Michael Williams**

cordially invites you to

**The 12th Annual Golf Outing**

**Saturday, September 21, 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

**Friends of Michael Williams**

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.

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
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<tbody>
<tr>
<td>General Donation</td>
<td>$______</td>
</tr>
<tr>
<td>Golf only ($140 per golfer)</td>
<td>$______</td>
</tr>
<tr>
<td>Dinner only - 4:00 p.m.</td>
<td>$______</td>
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<tr>
<td>$45 per person: # of guests</td>
<td>______</td>
</tr>
<tr>
<td>Raffle Tickets</td>
<td>$______</td>
</tr>
<tr>
<td>$5 each, 5 for $20, and 30 for $100</td>
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</tr>
<tr>
<td>Raffle Ticket order needs to be received by date of the event</td>
<td></td>
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**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
University of Chicago Awarded Annual Research Grant of $50,000

September 24, 2012

Dr. Susan Cohn
University of Chicago
5841 Maryland Avenue
MC4060, Room N114
Chicago, IL 60637

Dear Dr. Cohn:

The 11th 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 which includes $7,000 raised from the "Running with the Bulls" Pediatric Cancer Team in the Chicago Half Marathon race of September 9, 2012.

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 $50,000! 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  Dori Sexton
Chairman  Executive Director

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
Valentine's Day Thank You

February 7, 2013

Neuroblastoma Children's Cancer Society
Attn: Jim and Dori Sexton

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 in preparation for this Valentine's Day. We thank you for organizing the donation of teddy bears and gifts for the oncology patients. We know that these toys will help to brighten up the day of those needing it.

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 Loewry, M.S., CCLS
Child Life Specialist II
Hematology/Oncology Specialist
Pat Manning, Director
Child Life and Family Education

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 website at www.neuroblastomacancer.org.
The Neuroblastoma Children’s Cancer Society
partnering with
The Chicago Half Marathon and 5k 16th annual run
on September 9, 2012
"Running with the Bulls" Pediatric Cancer Team
for Pediatric Cancer Research

On September 9, 2012, NCCS "Running with the Bulls" Pediatric Cancer Team partnered with the 16th Annual Chicago Half Marathon with over 20,000 runners and over 100,000 fans, to raise money for pediatric cancer research.

Many family, friends and loved ones of NCCS participated and cheered on our Team. Our "Running with the Bulls" Pediatric Cancer Team was co-captained by neuroblastoma patient Matt Galvan and his Doctor (Dr. Sam Volchenboum from Comer Children’s Hospital at the University of Chicago). Bulls Legend Sydney Green presented awards to our runners and to Dr. Sam (pictured here) for his dedicated research to find a cure for neuroblastoma.

100% of the proceeds raised by our team went to fund neuroblastoma pediatric cancer research by Dr. Sam and Dr. Susan Cohn. On September 22nd, 2012, a check was presented to his colleague Dr. Susan Cohn at our golf outing, "Friends of Michael Williams" for neuroblastoma research in the amount of $50,000.

Matt Galvan, Jr. started and finished the race with encouragement from Bulls Legend Sydney Green (pictured here). Matt Galvan and many of the thousands of children affected by this disease were winners with the research supported by NCCS over the last 18 years. Michael James Sexton inspired us to start NCCS and a race where now more neuroblastoma patients can finish!

Thank you so much for your support and attendance and for "Making a Difference!"

Best Regards,
James F. Sexton
Chairman

www.neuroblastomacancer.org—check out our Wall of Fame Heroes for whom we ran!