

## The Safety Net of Pediatric Social Work

### Hope Street Kids Founder Randy Walker Addresses Pediatric Oncology Social Workers

Randy Walker addressed the membership of the Association of Pediatric Oncology Social Workers at their annual conference, stressing the need for health care professionals and families to serve as advocates to "make a critical difference in the lives of children with cancer and their families." Walker introduced the audience to Hope Street Kids' newest initiative — an innovative patient navigator program already in development at Columbus Children's Hospital.

Walker outlined the navigator concept that provides support to families from diagnosis through recovery. "This navigator can seamlessly guide parents and children through the continuum of care by providing support, information and assistance as necessary," he explained. "Many pediatric oncology programs lack the kind of continuity a patient navigator can provide," Walker added. "We hope the Columbus program will serve as the pilot for similar navigator programs in pediatric oncology programs nationwide."

Yvonne Bush has mastered the fine art of listening. And the voices she hears each day have taught her about frustration, fear, confusion and courage. Bush is a pediatric social worker at the Lombardi Cancer Center at Georgetown University, a job she calls "an awesome responsibility — and a unique privilege."

For four years, Bush tackled this task alone, tending to the emotional and social needs of hundreds of young cancer patients and their families. "It was at times overwhelming," says Bush. Now through a grant from Hope Street Kids, Bush has been joined by social worker Wendy Paramore — additional expertise Bush says is already making a tremendous difference.

"Now we can go beyond crisis management," she explains, "and become much more proactive." The Hope Street grant has allowed Bush and Paramore to expand several important initiatives including a school outreach program, a project to follow patients for years after treatment and a unique bone marrow treatment program targeted to the special needs of patients undergoing this difficult therapy.

A family confronted with childhood cancer is traumatized, Bush says. "It is an overwhelming experience that changes a family irrevocably." But immediate and sustained intervention by a social worker can ease both physical and emotional pain so that families can learn to cope and even thrive during the most frightening time of their lives.



Georgetown University Medical Center's pediatric social workers Yvonne Bush (left) and Wendy Paramore provide a comprehensive program of support for cancer patients and their families — during treatment and long after recovery.

"Most important to families is continuing routines and relationships that provide some normalcy," says Bush. For most children, normalcy means school, which is the central component of their lives.

Bush explains, "We are able to ensure that, despite hospitalizations and often harsh treatments, kids continue to learn and interact with their classmates." Teachers make home and hospital visits so that patients can continue their studies and a new computer system is helping the kids connect to their schools via the Internet. Now with the addition of Paramore, social workers can also make important school visits.

School visits help educate children and teachers before patients return to class. "Kids undergoing treatment are often anxious to return to school, afraid to face friends because they have lost their hair or because they feel they may be treated differently. Cancer can be very isolating for children," Bush says. "Some patients will try to hide the fact that they have cancer. But with a little counseling everyone is less afraid and the transition back to school is less difficult."

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## kids helping kids

### Children for Children Event Raises \$90,000

On March 10 at the Southern Theatre in Columbus, Ohio, more than 400 talented children from Central Ohio came together for the Second Annual "Children for Children" concert to benefit Hope Street Kids.

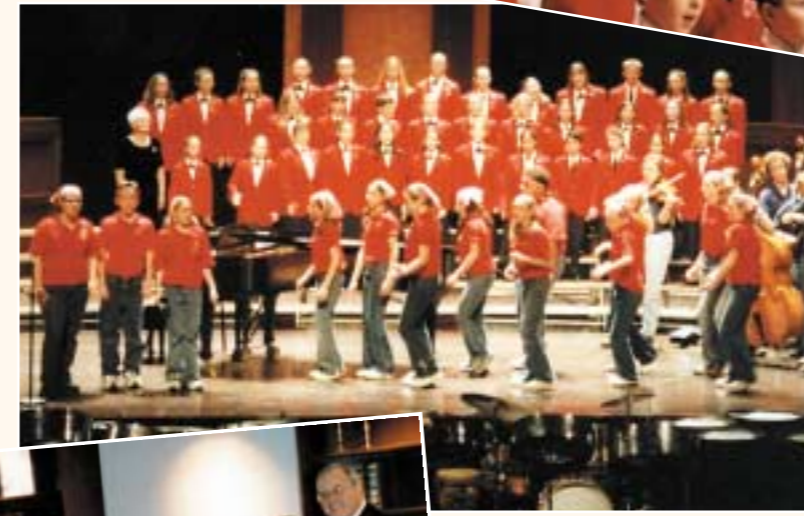
Entitled "Celebrate America," the event highlighted patriotic songs and music by American composers and featured the Columbus Children's Choir. Special guests included Mayor Michael Coleman, his wife Mrs. Frankie Coleman and emcee Gail Hogan, anchor and reporter for WCMH-NBC 4. The children raised \$90,000 to benefit Hope Street Kids.

The concert also included the Gahanna Fiddlers, Arts Impact Middle School Steel Drum Band, Columbus Alternative High School Chorale, Columbus Youth Chorale and Columbus Symphony Cadet Orchestra, as well as Columbus Children's Choir soloists.

Dr. Sandra Mathias, Artistic Director of the Columbus Children's Choir, said, "The Children for Children project is a way for talented young artists in central Ohio to develop a sense of stewardship." Children also take part in the "Children for Children Makes Cents" penny collection program in schools throughout the state. "In giving of their time, talent and pennies, all of these youth strive to help other young people," Dr. Mathias said. The top school, Saint Mary School in Lancaster, Ohio, collected nearly \$250 in pennies.

Event sponsors included: National City, Giant Eagle, American Electric Power, Battelle, Nationwide, Honda of America Manufacturing and Vivendi Universal.

For information about supporting next year's event, please call Julie Barry at 614-228-4820.



Gary Glaser, Chairman, National City, Central Region, presents a check for \$10,000 to Morgan Black of the Columbus Children's Choir for sponsorship in the "Children for Children" event on March 10, 2002 at Columbus' Southern Theatre. Also pictured left to right are Rose Schworm of Columbus Children's Choir, Mike Gonsiorowski, President and CEO, National City, and Randy Walker and Congresswoman Deborah Pryce, Founders Hope Street Kids.

### Holiday Concert by Kids, for Kids

The holidays can be a tough time to be a child in the hospital. A group of girls from the Columbus Children's Choir brought their beautiful voices and holiday cheer to the kids in the Hematology/Oncology floor at Columbus Children's Hospital. On December 19, 2001, the choir joined Hope Street Kids Co-Founder Randy Walker to deliver cards and songs to the children and their families. "The holidays are a hectic time for everyone. What a statement it makes about the caliber of kids in the Columbus Children's Choir that they were willing to take the time from friends, school and holiday shopping to spread the true meaning of the holidays to those who need it most," said Walker.

## Spotlight on...

### An Evening at the Columbus Zoo

Please join us on August 17, 2002 for a spectacular family affair that features music, great food and of course — lots of animals. This year's Third Annual Caroline Pryce Walker Memorial Event will be held at the Columbus Zoo and Aquarium in Powell, Ohio from 6 to 10 p.m. Tickets are \$75 per family.

Corporate sponsorship opportunities are available.

The 2002 event is expected to draw more than 1,400 people. Proceeds will support the Hope Street Kids Pediatric Cancer Research Grants and Fellowships program. For more information on the event, please call 614-228-4820.

### National City Supports Hope Street

Generous benefactor National City Bank has provided a \$70,000 gift to fund a Hope Street Kids' research grant or fellowship. The named grant or fellowship will be announced at a June 2002 press conference and will provide support for one of the most promising research proposals identified

by the Scientific Advisory Council.

To learn more about the National City Bank gift, visit [www.hopestreetkids.org](http://www.hopestreetkids.org). If you are interested in ways you or your business can support a named grant or fellowship, contact Cynthia Duncan at 1-800-227-2732.

## Mark Your Calendar

**The Third Annual "Swinging for Caroline" Golf and Tennis Invitational**  
Monday, June 10, 2002  
Lansdowne Resort  
Leesburg, Virginia

For more information, contact Cynthia Duncan at 1-800-227-2732.

**Caroline Pryce Walker Memorial Event at the Columbus Zoo**  
August 17, 2002  
Columbus Zoo and Aquarium  
Columbus, Ohio

**Conquer Kids' Cancer Gold Ribbon Rally**  
September 25-27, 2002  
Capitol Hill  
Washington, DC

Congresswoman Deborah Pryce



### Founder Pryce Talks Advocacy at ASPH/O Conference

Congresswoman Deborah Pryce, Hope Street Kids founder, addressed the 15th Annual Meeting of the American Society of Pediatric Hematology/Oncology (ASPH/O) as keynote speaker and related her compelling personal story, emphasizing the critical value of collaboration within the pediatric oncology community. Pryce, who recently became an affiliate member of the Society of distinguished leaders in pediatric hematology-oncology, said, "Our most effective efforts come if we pull our time, resources and energies into one voice speaking for children suffering with cancer." The impact of many organizations acting in partnership will have a strong influence on legislative action to improve pediatric oncology services and increase funding for research, Pryce said.



## The Promise of Microarrays —

Mapping the Future of Cancer Treatment

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The picture, however, is pure science. Through the use of bio-informatics — a software program that analyzes nearly 300,000 bits of data — the patterns reveal a cell's genetic makeup. The graduated shades of color tell Wang and Maris which genes are important in the lifecycle of a particular cancer cell.

“Some genes are turned on or highly expressed in some cancer cells and others are not,” explains Maris. “These appear in varying intensities of color on the computer screen. The images will help us understand the molecular differences between one tumor type and another.”

In particular, Maris explains, Wang will compare the “gene expression profiles” of the high-risk tumors to those that can be treated with success. This understanding of the biology of the tumors may ultimately lead to drugs that target unique genes — and result in increased survival.

“The information Dr. Wang is gathering will help us develop a “prognostic panel” for patients with neuroblastoma,” adds Maris. “It will tell us the unique characteristics of a patient's tumor and allow us to more accurately treat that tumor type. And as the patient's treatment progresses, we can prepare a new panel to determine if the therapy is succeeding.”



This small microarray chip holds 300,000 bits of information about the genes of a neuroblastoma cancer cell.

All of this data will become part of a national data bank that's shared with pediatric cancer researchers across the nation — an aggregation of critical information that will help other scientists develop more effective therapies for a host of pediatric cancers.



## First-ever Sarah Howard Fellow

**Dr. Qun Wang is the first-ever recipient of the Sarah Howard Childhood Cancer Fund Fellowship, which was created in memory of 11-year-old Sarah, who died in 1999 of Ewing's Sarcoma, a rare form of bone cancer.**



Sarah Howard

The Howard Family of Alexandria, Virginia — parents Julie and Bill, brother Brooks and sister Annie — wanted to, “create something positive from this devastating experience,” says Julie. Funded initially by seed money donated by the Howard family, the Fund has grown through private donations and the annual Sarah Howard Golf Tournament.

“We are thrilled by the response of our friends and neighbors,” says Bill, “and gratified to see these funds going to such a worthwhile investigation.” The Howards recently visited the Children's Hospital of Philadelphia, met with Drs. John Maris and Wang, and toured the lab to see first-hand their support at work.

“I was so impressed with their intelligence and dedication,” Julie says, of Wang and Maris. “And we both feel encouraged that the work they are doing will have a real impact on improving treatment for not only neuroblastoma, but for other cancers as well. It's also encouraging to know that no matter how devastating the loss, we can do some good as a family to fight childhood cancer.”

Annie, Julie, Bill and Brooks Howard are honoring the memory of Sarah through a named Hope Street Kids fellowship.



## The Safety Net of

Pediatric Social Work *continued from page 2*

Social workers create a safety net for families, where medical, psychological, emotional, even financial crises are confronted and resolved. And this safety net should not disappear after treatment ends. As more children survive cancer and grow into adulthood, the complex issues of survivorship surface. The Late Effects Clinic now underway at Lombardi is providing crucial follow-up support for children and families, assessing children routinely at visits every three to six months for the first few years post-treatment and yearly thereafter.

Lombardi's expanded bone marrow transplant program created new challenges for social workers and families. It is an intense therapy that creates guilt, isolation and financial concerns.

Now Bush can offer the kind of intervention that is critical for these families. “They need resources other families may not, and need to know that they can seek refuge in a safe place.”

This is the predominant theme in all pediatric oncology social work, adds Bush. “The trauma of a childhood cancer diagnosis threatens the essence of the family. But they ultimately find strength with guidance and support.

“In the end, childhood cancer changes lives — sometimes for the good. Children are wise beyond their years and deeply understand what is truly important in life.”



Nine-year-old Caroline Pryce Walker, who lost a courageous battle in September 1999 against neuroblastoma.

## Scientific Advisory Council



**The Hope Street Kids Scientific Advisory Council, a panel of leading cancer experts, reviews proposals for research in treatment and prevention of childhood cancers following the National Institutes of Health grant-review standards. The Hope Street Kids grant and fellowship program is non-federally funded and is privately supported through individual, corporate and foundation contributors. Thank you for your continued support.**

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*Hope Street* is published by Hope Street Kids, a pediatric program of the Cancer Research Foundation of America. **Its mission:** to eliminate childhood cancer through advocacy, education and cutting-edge research, and to help support children with cancer and their families during and after treatment.

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# HOPE Street

News from *Hope Street Kids*, a pediatric initiative of the Cancer Research Foundation of America.

## The Promise of Microarrays —

Mapping the Future of Cancer Treatment

**Predicting the future becomes fine art with the application of computer technology to biology. At the Children's Hospital of Philadelphia, researchers Drs. John Maris and Qun Wang are successfully blending the two disciplines to develop a system of sophisticated prognostication with the potential to save the lives of hundreds of young cancer patients.**

“Understanding of the biology of tumors may lead to drugs that target unique genes — and result in increased survival.”

### What's inside

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Dr. Maris heads a unique laboratory at the Hospital devoted entirely to the study of more effective treatments for a devastating childhood cancer — neuroblastoma. Wang, a post-doctoral trainee in the lab, is the recipient of Hope Street Kids' Sarah Howard Fellowship. She is using computers to untangle a web of information held in the genes in these tumors — data the researchers believe will be lifesaving.

Neuroblastoma is a cancer that begins in the nerve tissue of infants and young children. Most often diagnosed before age five, it spreads to other parts of the body including the liver, lungs, bones and central nervous system. Of the 600 children diagnosed with neuroblastoma annually, more than half will die. Others respond well to treatment and are cured by surgery or surgery with chemotherapy. Understanding why these differences exist is crucial to improving survival rates: Maris and Wang feel the answer lies in the complex genetic material within the cancer cells.

Applying the increasingly popular — and rapidly advancing — research technique called microarrays, Wang is mapping the genes found in four different types of neuroblastoma tumors, including those high-risk tumors that resist treatment. Genetic material is withdrawn from tumor samples, labeled with a fluorescent color and put on a “gene chip,” which has been coded to examine genetic material. The chip is scanned and a computer image appears as intricate patterns of color blocks resembling a contemporary painting.