



# Hope Street Kids

LEADING THE FIGHT AGAINST CHILDHOOD CANCER



Congresswoman Deborah Pryce, Congressman Michael McCaul on the East Steps of the Capitol at Gold Ribbon Days.



Congresswoman Deborah Pryce tells the audience she will continue working for pediatric cancer issues.

## Conviction and Courage Equals Change

**“She understands how I feel when I’m fighting for my child’s life,” said a mother after hearing Congresswoman Deborah Pryce speak on the steps of Capitol Hill about the importance of pediatric cancer research on June 21, 2006, during this year’s Gold Ribbon Days.**

The annual event brings families, caregivers, and pediatric cancer organizations to Washington, D.C., to advocate on behalf of children diagnosed with cancer. It is a valuable time for families to talk with their legislators about their personal stories and their hopes for a cure.

This year’s event celebrated the children who bravely tackle cancer, the successful endeavors achieved by legislators and advocates, and the television premier of a documentary mini-series that takes an unprecedented look at the lives of five young people living with cancer and the disease’s impact on them and their families.

Earlier in June, a Congressional briefing held at the Capitol launched

the special documentary on the award-winning PBS program, *Independent Lens*. At the core of the mini-series, “A Lion in the House,” are five extraordinary young people who inspire us with their resilience, courage, and wisdom. During her remarks at the briefing, Hope Street Kids Co-Founder Rep. Pryce tearfully stated, “For those of us who have traveled on our own journey, this film depicts our experiences, our struggles, and our pain. For those of you who have not traveled on this journey, this film will give you empathy and compassion.” Hope Street Kids is a national partner on this film project.

Also during this year’s Gold Ribbon Days, House Resolution 323 was passed in the House to raise awareness

*continued on back*

September is National Childhood Cancer Awareness Month





Nate Tomberlin, age 5, swinging for Caroline.



L to R: Congressman Roy Blunt, Congresswoman Deborah Pryce, and Congressman Tom Latham



L to R: Dan Roehl, Shiloh Roehl, Peter Begans, and Bill Head

## Seventh Annual Swinging for Caroline Golf and Tennis Invitational

The Army Navy Country Club in Arlington Virginia was the setting again for the “Swinging for Caroline” Golf and Tennis Invitational, this year held on June 19th. Fifty golf foursomes, a dozen tennis players, and numerous families enjoyed a day of swinging clubs and racquets and swimming in the pool, all in support of Hope Street Kids. This year’s event raised more than \$600,000 in support of Hope Street Kids’ Pediatric Cancer Grants and Fellowships – awarded annually to researchers around the United States who are searching for novel approaches for the treatment and cure of cancer.

Golfers at the tournament participated in a scramble best ball format and tennis players participated in a round-robin format. Several Members of Congress and their staffs were able to participate in events during the day, including The Hon. Roy Blunt (MO), The Hon. Charles Boustany (LA), The Hon. Tom Latham (IA), The Hon. Jim McGovern (MA), and The Hon. Deborah Pryce (OH). Families enjoyed a pool party and kids’ tennis clinic and were entertained throughout the day by characters from Six Flags. A luncheon and awards ceremony followed the golf and tennis tournament where awards were presented to golfers and tennis players in team and individual categories. A highlight of this year’s ceremony was a Silent Auction featuring a Broadway Trip and a Disney Trip – competition throughout the day was fierce, from the golf course to the tennis courts to winning the silent auction!

Special thanks to Diane Tomb and Paula Timmons, JC Scott and Clint Robinson, John Timmons, Debbie LeHardy and Mike Tomberlin, plus the fantastic Finance Committee. They are a special group of people to work with and their leadership, commitment and hard work culminated in the success of the day.

Comments were given at the awards ceremony by HSK Co-Founder Congresswoman Deborah Pryce, HSK Scientific Advisory Council Chairman Dr. Stephen Chanock, and HSK Executive Director Beth Westbrook. All spoke of the vision of Hope Street Kids – a world without childhood cancer and their appreciation for all of the participants in this year’s “Swinging for Caroline”. ●

*This year’s event raised more than \$600,000 in support of Hope Street Kids’ Pediatric Cancer Grants and Fellowships.*





Carolyn Coveney and James Runde wait for the walk to start. While both children were diagnosed with neuroblastoma, Carolyn has finished treatment at MSKCC and James is in treatment at MSKCC.



Each person walked for his, or her, own reasons. Everyone participated to move one step closer to a victory over pediatric cancer.



Casey Lafer (in the background), co-chair of the Kids Walk, gathers the children to start everyone walking.

## Kids Walk for Kids with Cancer

Saturday May 13th 2006 • Central Park, NYC



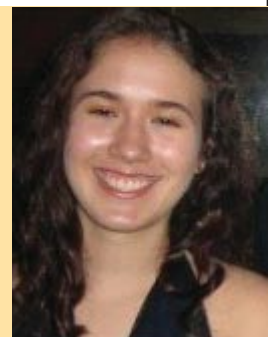
A small mass of people have assembled near the 67th Street entrance of Central Park on a sunny Saturday afternoon. Many of them are sporting bright red T-shirts with the words “Kids walk for kids with Cancer” printed across their chests; and indeed, the vast majority of this crowd has not yet graduated from high school. Kids of all ages are running around on the grass shrieking and giggling while more and more people arrive to join the group. This is the 6th annual meeting of a fundraising event run by New York City high school students trying to help in the fight against pediatric cancer. The event is a 4.5-mile walkathon which first raised \$35,000 in 2001. Today’s walk in 2006 will later raise over \$100,000 which will be donated in full to Memorial Sloan Kettering Cancer Center in New York City and used for pediatric cancer research.

This was the first time that I have attended the event, and after the day’s experience I know it will not be my last. It is a pretty amazing feeling to be part of a group of people my age who are honestly trying to help others as best as they can. The energy and spirit which goes into organizing the event and making it happen is remarkable; it makes me proud to know that I have been part of the effort. This year raised 1/3 of the total sum that the walk has gained since 2001 and hopefully next year we will accomplish even more. ●

– Bailey Georges



Bailey was a summer high school intern at Hope Street Kids in August of this year. As part of the Kids Walking for Kids with Cancer, participants may spend part of their summer helping the staff in Alexandria, VA. If you are interested in learning more about summer internship opportunities, please contact Beth Westbrook at 703.519.2107 or [beth.westbrook@preventcancer.org](mailto:beth.westbrook@preventcancer.org).



[www.hopestreetkids.org](http://www.hopestreetkids.org)

Summer Internship Opportunities. 703.519.2107

## Measuring Stress for Greater Success



\* For most families, the cancer diagnosis of a child is a painful and frightening experience. Still, the majority of them find the emotional reserve they need to deal with the strain of treatment,— and hopefully, recovery. For others, the path through treatment is fraught with stress and the potential for emotional strain from which they may never recover. \*

**D**r. Sunita Patel, a clinical neuropsychologist at the City of Hope National Medical Center, says early intervention is critical to success for these children and their families but identifying those who are not coping well isn't always easy. All families suffer anxiety for about six months following a cancer diagnosis, says Patel. "For most, over the course of time there won't be the same stress level. But there is a subgroup of families who continue to feel very anxious and stressed years later – and may hide their distress very well."

Especially in large, busy cancer centers, families may sometimes fall through the cracks, and don't receive the type of support they need. To minimize this situation, the NCCN guidelines recommend that each cancer patient should ideally be screened for distress using a rating scale of 0 to 10 – much like the pain scale rating in use today. This scale is increasingly incorporated into clinical care at major adult cancer centers, but has not yet been validated or evaluated for use in the pediatric oncology setting. Furthermore, little is known about the utility and application of this type of distress screening in tailoring and providing interventions to patients and their families.

"We know little about what happens in the oncology clinical setting once the

distress rating/assessment is obtained", Patel explains. That's why she is conducting a pilot study to evaluate the validity and utility of using this screening strategy to detect distress in pediatric cancer patients and their primary parent caregivers. In this study, Patel has expanded upon the simple screening procedure by obtaining distress ratings from various perspectives to not only validate the tool, but also to understand if there are discrepancies between the patient, parent, physician, and psychosocial staff in the perception of emotional distress exhibited by the cancer patient and his or her primary parent.

Patel believes this type of multi-informant screening system, if implemented in routine clinical practice, would increase the chances of detecting those families that are in need of intervention. Furthermore, a standardized but practical assessment strategy may also assist with allocation of limited resources in the busy cancer treatment environment. This system garners information from not only the patient, but from the patient's chief caregiver (most often the mother), the medical team and the psychosocial team assigned to care for the child. The team of professionals are also asked to complete a checklist to indicate what they believe is causing the patient's distress.

"In this way we get many perspectives from which we can then determine the distress category (mild, moderate, high) to which services should be matched," Patel says. "Families with low distress may have different needs relative to families with high distress.

Theoretically, the frequency, quantity and type of psychosocial interventions provided to patients and their families would differ based on their need and distress level. This study is a preliminary step in evaluating if these expected differences do indeed exist in the clinical setting. The eventual goal is to create a minimum standard of emotional support and intervention that corresponds to each of the three categories of distress," she explains.

Patel has begun her pilot study and has enrolled 91 patients/families over the course of one year. The distress level of the patient and primary parent caregiver is evaluated every three months beginning from the first day of study enrollment. The patients' emotional distress, along with his or her medical status, is carefully tracked for a year. Dr. Patel hopes to learn about what happens "naturally" in the clinical treatment setting, in regards to distress assessment and follow up services, so as to build upon the findings to develop effective triage strategies to inform practical care. ●



**Dr. Sunita Patel**  
is the recipient of  
a grant from  
Hope Street Kids.



[www.hopestreetkids.org](http://www.hopestreetkids.org)

# High Five for Helping



Each newsletter, Hope Street Kids will be highlighting an organization or donor that has made a special contribution. We will ask them five questions to learn about their involvement with HSK and hopefully inspire others to become involved.

This month we are talking with Wendy Bradshaw, Executive Director of the Columbus Blue Jackets Foundation. Wendy brings passion and enthusiasm to everything she does and reminds us that change can begin with one person and then grows.

## How did you become involved with HSK?

The Columbus Blue Jackets Foundation's number one initiative is to raise money for pediatric cancer. We became involved with Hope Street Kids when our charitable Foundation's Board of Directors selected HSK to receive a \$10,000 grant in support of its research efforts. We were excited to partner with a reputable local non-profit organization dedicated to pediatric cancer research. To date our support of pediatric cancer has been limited to programming and family support. This allowed us to get involved on the research side.

## Since the first time, in what ways have you worked with HSK?

To date the Columbus Blue Jackets Foundation has granted over \$60,000 to Hope Street Kids in support of the palliative care research and educational project at Columbus Children's Hospital.

We participate in the annual Caroline Pryce Walker Memorial Event at the Columbus Zoo and Aquarium. Blue Jackets players have been involved in PSAs to promote the upcoming event. Guests of the event can always count on visits from our team mascot Stinger and appearances from Blue Jackets players on stage to award door prizes and endorse the organization.

Columbus Blue Jackets Foundation volunteers worked at The Bogey Inn during the Memorial Tournament to sell wrist bands in support of increasing awareness for the cause.

## Is there one moment that stands out as extra special?

I think the zoo event when we tied our support for HSK all together with an appearance from Blue Jackets player Tyler Wright, the captain of the pediatric cancer initiatives, who endorsed the cause and educated the audience on our

GOAL to fight Pediatric cancer as a league. Stinger was there to entertain the kids and we distributed Blue Jackets door prizes. This was not the typical Blue Jackets player appearance for us but rather an extension of our partnership with a local grant recipient dedicated to fighting pediatric cancer.

## Why do you do it? Why support pediatric cancer issues?

The Columbus Blue Jackets Foundation selected pediatric cancer as its number one pillar of giving in support of the National Hockey League's Hockey Fights Cancer initiative. Through this league wide program, all the teams are asked to participate in local events and programs to raise funding and awareness for cancer initiatives. There have been many members of the NHL family that have been afflicted with cancer so the league developed this program in support of its family of players, coaches, and referees.

The Foundation feels strongly that pediatric cancer is a cause that often does not get the attention of some of the other causes and it believes utilizing professional athletes to be a voice for this cause is a strong credible endorsement.

## What will you say the day a cure for childhood cancer is announced?

Together we reached our GOAL! ●



Columbus Blue Jackets Foundation Hero Sullivan Plancon. Sullivan is currently being treated at Columbus Children's Hospital.

Make a Difference. 703.519.2107



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

The mission of Hope Street Kids is to eliminate childhood cancer through pioneering research, education and advocacy and to help support children with cancer and their families during and after treatment.

The **Cancer Research and Prevention Foundation** is recognized by the IRS as a 501 (c) (3) public charity and meets all standards of the National Charities Information Bureau. Your gifts are tax deductible to the fullest extent allowed by law. Hope Street Kids is registered as a DBA under CRPF.

**Co-Founders**

Congresswoman Deborah Pryce  
Randy Walker

**Executive Director**

Beth Westbrook Starnes

**Cancer Research and Prevention Foundation President and Founder**

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## Conviction and Courage,

*continued from front*

about pediatric cancer. On the final day of the 2006 event, a rally held on the east steps of the Capitol gave the attendees one more chance to talk about childhood cancer and the important step of passing HR 323. With a large crowd of families and caregivers standing in support of Rep. Pryce, the congresswoman addressed those gathered on the steps.

“It is human nature to question the sanity and injustice of why such a tragedy has befallen those of us who have been touched by cancer,” she said. “We must find a way to channel our pain and our anger into action to change the course of this disease. That is what Gold Ribbon Days is all about, and this resolution is part of our action plan.” ●



Tim and Donna Culliver tell the story of their son's battle with cancer. Standing next to them are Congresswoman Deborah Pryce and Congressman Michael McCaul.

*We must find a way to channel our pain and our anger into action to change the course of this disease.*

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**Hope  
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Kids**

LEADING THE FIGHT  
AGAINST CHILDHOOD CANCER

1600 DUKE STREET, SUITE 500  
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A PROGRAM OF THE  
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