

# HOPE HAPPENS

Chris Hobler's dream of  
collaborative translational  
research in action!



Winter/Spring 2008 Newsletter

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

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## Save the Date

the fourth annual  
evening of  May 14, 2008

Please join us for the fourth annual *Evening of Hope* at the Sheldon Concert Hall, 3648 Washington Blvd. on Wednesday, May 14, 2008. Doug and Vicki Hill are Honorary Co-Chairs of the event.

The fourth annual *Evening of Hope* will star violinist Anne Akiko Meyers, "one of the world's leading soloists, recitalist and chamber musicians, capturing the hearts of audiences and the imagination of composers." Here is a link to her website: <http://www.anneakikomeyers.com/home.php>.

"This event creates awareness about the Hope Center and raises funds necessary to continue the research for cures for neurological diseases," said Hope Happens Executive Director Dennis O'Brien. "Our unique cross-disease strategy takes advantage of disease-related commonalities and

economies of scale to maximize the effect of every donor's philanthropic investment."

Edward Jones and Maritz Inc. are the Principal Sponsors of the event. Carol and Bert Walker, Susie Philpott and Jean Hobler will co-chair the event. Kathleen Rogers and Carrie Martin will co-chair the Patron Committee.

Tickets for this enchanted musical evening are \$250 per person. Sponsorships are available at various levels, beginning with Patron at \$1,000 per couple up to \$10,000 for a platinum sponsorship. Performance only tickets are available for \$20 through Metrotix or the Hope Happens office.

The evening will begin with cocktails, dinner at 6:30, and the concert at 8:00, followed by a reception with the artist at 9 p.m.

For more information or to purchase tickets, please contact Elisa Donnelly at 314.289.5660.

## Hope Happens Recognizes Inspirational Leader



Jean Hobler, a 2007 Woman of Achievement, was recently named Co-Founder with permanent membership on the board to recognize the invaluable role she played in establishing Hope Happens along with her son Christopher Wells Hobler and other family members.

"Jean's passion to cure ALS and other devastating neurological disorders has inspired many others in the community to take up the challenge," said board president Jeff Hercules. "She has been and

remains an invaluable force in bringing support to this critical effort to find cures for disorders that are often thought of as incurable."

Chris Hobler was diagnosed with Lou Gehrig's disease in 2001, twenty years after his grandfather, James H. Maritz, died of the disease. He was fiercely determined to find cures when he learned there had been no progress in treatment between his diagnosis and his grandfather's death. Chris was convinced that the search for cures for neurological disorders could be greatly accelerated if researchers would share their findings across diseases and disciplines. His conviction led to the creation of Hope Happens, a nonprofit organization dedicated to improving the lives of people with neurological disorders by promoting collaborative efforts to fast-track the translation of basic research into cures.

Hope Happens partnered with Washington University School of Medicine to establish the Hope Center for neurological research with the goal of rapidly bringing new treatments and cures to patients afflicted with a wide range of neurodegenerative disorders.

Chris Hobler lived to see the Hope Center open in January 2005 before he died on February 16, 2005.

## The Need for Cures — Enormous!

Disorders of the nervous system are the most common causes of disability for people of all ages. **More than fifty million Americans** have a permanent neurological disability that limits their daily activities; many are progressive or even fatal. And the numbers keep growing. In fact, 7,650 Americans are diagnosed with a nerve-killing disorder every day—3 times the number as those who are diagnosed with cancer. Of these, more than 3,100 are children—more children than the number of people that perished in the terrorist attacks of 9/11/2001!

1 person is diagnosed with a prion disease.

4 people are diagnosed with Huntington's disease.

14 adults receive a death sentence when diagnosed with ALS.

22 babies are born with Cerebral Palsy.

27 people learn they have Multiple Sclerosis.

36 suffer a spinal cord injury, including 6 who die of their injuries.

357 children are diagnosed with epilepsy.

380 people are diagnosed with Parkinson's disease.

961 learn they will lose their identity to Alzheimer's disease.

2,000 suffer a stroke.

3,846 receive brain injuries (including 2,747 children), with 220 suffering permanent damage and 137 dying of their injuries.

As the number of victims increases each day, so does the need for cures. "We believe it is not enough to simply find new treatments," said Hope Happens board member John Brightman. "We are determined to find cures." Brightman is also vice chairman of UMB Bank.

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## Universities Concerned about Medical Research Within Our Grasp—Or Slipping Away?

Washington University and seven other prestigious medical centers recently published A Statement by A Group of Concerned Universities and Research Institutions to call attention to the "looming crisis of diminished resources and research" due to the "funding crisis" at the National Institutes of Health (NIH).

### Looming Crisis

After pointing out that many breakthroughs in medical research had been achieved in part because NIH funding had doubled from 1998 to 2003, they decry the steady decline in NIH funding over the past four years. The funding crisis means that "eight of 10 grant applications now go unfunded, according to NIH figures," the report said.

As a result, "scientists are being forced to downsize their laboratories and abandon some of their most innovative and promising work. These conditions may also be putting at risk a generation of young researchers," the report said. Tragically, this "comes at a time of escalating threats to human health."

### Implications for Hope Happens Donors

"Two things are eminently clear," said Hope Happens Executive Director Dennis O'Brien. "First, the need for philanthropic support of medical resource has never been more important or urgently needed than now. Secondly, the unique, cutting-edge collaborative mode of doing translational research at The Hope Center maximizes the potential impact of every dollar our donors give. Breakthroughs are much more likely to come through this collaborative, translational approach than by scientists focused on a single disease."

This report can be read in its entirety at [www.hopehappens.org](http://www.hopehappens.org).

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## Dana Brown Makes Leadership Gift

The Dana Brown Charitable Trust recently pledged \$100,000 to Hope Happens to support collaborative translation research to find cures for neurodegenerative disorders that occur when brain cells and their connections are damaged.

Dana Brown was a well-known personality in St. Louis due in part to his many appearances on television representing Safari brand coffee and sharing his latest adventures while on safari in Africa. Originally from West Virginia, Mr. Brown adopted St. Louis as his home and had a deep affection for the region. To his friends, Brown was best known for his kindness, generosity and spontaneous spirit. Shortly before his death in 1994, he established a grant-making foundation to benefit children in the St. Louis metropolitan area, especially disadvantaged children.

“These funds will improve, and in some cases prolong, the lives of many thousands who will

benefit from the new treatments and cures developed by Hope Center scientists,” said David M. Diener, Vice President, U.S. Bank and Co-Trustee of the Dana Brown Charitable Trust. “This would certainly seem to meet the desires of Mr. Brown to enhance the lives of, and expand opportunities for, children, including those who may be minorities or otherwise disadvantaged.”

Each day another 7,650 Americans are diagnosed with a neurodegenerative disorder, including more than 3,100 children. For example, 22 babies are born with Cerebral Palsy, 357 children are diagnosed with epilepsy, and 2,747 children suffer brain injuries each day.

“We are very grateful for this leadership gift from the Dana Brown Foundation,” said board president Jeff Hercules. “It will help us accelerate the pace by which cures are found for neurological disorders that are often thought of as incurable.”

## Laughlin Foundation Supports Hope Happens

The Laura K. Laughlin L6 Brain Injury Foundation made its first grant to support research to fast-track cures for neurological disorders on what would have been Laura Laughlin’s 28th birthday, Dec. 2, 2007.

“Laura’s birthday is the perfect time for us to begin funding the collaborative research promoted by Hope Happens to find cures for traumatic brain injury and other devastating and often fatal neurodegenerative disorders,” said Amy Bratton, the foundation’s executive director, who hand-delivered a check for \$3,000. “Laura would be delighted that the first grant the foundation has made goes to support cutting-edge research conducted at the Hope Center and that it was made on her birthday.”

Although the gift was less than they had hoped it would be, the foundation trustees expect to continue this support to Hope Happens and increase it. “If we knew we could raise it, we would pledge more now,” Bratton said.

“We are very grateful for this gift and look forward to a mutually supportive, ongoing relationship between our organizations,” said Hope Happens Executive Director Dennis

O’Brien. “We are both committed to expanding public awareness and raising funds to support collaborative, translational research to find cures for nerve-killing disorders that afflict an additional 7,650 people each day, including 3,846 who receive a traumatic brain injury like Laura suffered.”

The organizations share another link. Dr. David Brody, PhD, MD, who was Laura’s physician and serves as a director of the foundation, is also on the Hope Center Faculty.

For a link to the foundation’s Web site, visit [www.hopehappens.org](http://www.hopehappens.org).

### Visit The Hope Center - Learn How Hope Happens

Meet the scientists who direct the center and learn how collaboration helps them fast-track the search for cures. Call 314.289.5660.

# Hope Chief Advises Post-Dispatch

## — Paper recruits O'Brien to serve on its advisory committee

Hope Happens Executive Director Dennis O'Brien was invited to serve on the newly formed Community Advisory Board of the *St. Louis Post-Dispatch*. The paper recruited "a group of thoughtful people with a wide range of interests and expertise to help (the editorial staff of the *Post-Dispatch*) focus and guide discussions of issues critical to our region's future."

At the first meeting of the Community Advisory Board, 50 members of the board and 15 members of the *Post-Dispatch* news and editorial staff spent three hours identifying the issues they believe to be most important to our region's future. The committee identified five priorities for the region:

- **Economic Development**
- **Health Care**  
(including "better access for all" and ways "to preserve the high quality of medical research that is being done in area medical schools" such as the collaborative translational research at The Hope Center)
- **Racial and Cultural Polarization/Social Equity**
- **Regionalism**
- **Schools/Positive Youth Engagement**

"I contributed to the discussions, served as spokesperson for my group and suggested edits that were incorporated in the initial article announcing the formation of the article," O'Brien said. "I am very impressed by the quality of community leaders the *Post-Dispatch* has recruited for this important task. I hope that I can help stimulate thoughtful reflection and positive action in the region by my involvement in this remarkable initiative by the *Post-Dispatch*, especially in areas I am most qualified to address, such as schools, youth engagement and health care."

"I commend Kevin Mowbray (publisher), Arnie Robbins (editor), Pam Maples (managing editor), Christy Bertelson (deputy managing editor), Jamie Riley (editor of letters to the editor) and other leaders of the *Post-Dispatch* for launching this innovative and very promising effort to use the paper as a catalyst to bring together community leaders who have the talents, proven track records and passionate commitments to help improve the quality of life off all our citizens by stimulating action to address these five regional priorities," he said. "The recent hiring of Gilbert Bailon as Editor of the Editorial Page will give this effort new momentum. All of us hope that, by working together and with support from the *Post-Dispatch*, we can advance this agenda of regional dialogue and change."

For links to more about this committee, visit [www.hopehappens.org](http://www.hopehappens.org).

## Hope Center Expands Faculty

The faculty of the Hope Center has grown by 25 percent over the last year, expanding from 52 Primary Investigators (PI) to 64. Since each PI heads a team of scientists, almost 500 researchers are now doing collaborative translational research at the center.

This dramatic growth since the center opened in January 2005 reflects the validity of Chris Hobler's dream of collaborative research to fast-track the search for cures. It also reflects the fact that Hope Center scientists are making breakthroughs that show great promise of leading to cures, such as:

*A breakthrough gene therapy shown to slow or stop progression of Parkinson's disease.*

*Evidence that certain types of nerve damage caused by Alzheimer's disease can be undone, suggesting that some symptoms of the disease may be reversible.*

*Identification of a protein that delays the breakdowns of axons, the part of the brain cell that broadcasts nerve impulses to other neurons. This has implications for new treatments for ALS, Alzheimer's, MS and other neurological disorders.*

Finally, this growth reflects the world-class status of the scientists at Washington University and the outstanding work of its leadership team: Dr. David Holtzman, Chair, Neurology; Dr. Mark Goldberg, Director; and Dr. Anneliese Schaefer, Deputy Director.

# A Special Thanks to all of our Hope Happens Donors

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## Hope Center Awards Translational Research Grants

For more information, visit [www.hopehappens.org](http://www.hopehappens.org).

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# HOPE HAPPENS

for Neurological Disorders

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## *Our Mission*

*To improve the lives of people with neurodegenerative disorders by promoting collaborative, translational research with the potential to fast-track cures.*

## Hope Happens Expands Board

Hope Happens has added three community leaders and expanded its board of directors to 17. **Mary Bettis**, Director of Process Improvement, Sigma-Aldrich, has led her division to win four industry-wide awards. **Aimee Davis**, Worldwide Marketing Communications Manager, Solutia Inc., previously served 12 years as the public relations director of Life Skills Foundation. **Glen Holt**, Consultant and Writer, is the former Executive Director of the St. Louis Public Library.

“Mary, Aimee and Glen bring experience, valuable skills and strong personal commitments to our cause,” said Hope Happens Executive Director Dennis O’Brien. “The also deepen our connections in the St. Louis philanthropic community that must support our efforts to find cures in order to ultimately benefit from them. I am very excited they have joined us.”

## New Response Envelope Reflects Search for Multi-Year Pledges

The response envelope has been revised to make it convenient for donors to make a larger gift spread over several years. According to the Philpott family, one of the first donors to make a multi-year pledge, doing so makes sense from a donor’s point of view. “We spend a lot of time and effort evaluating each grant request, and making a three-year pledge like this is much more efficient for us and effective for the recipient.”

Multi-year pledges are very important to Hope Happens. “Knowing that there is a committed stream of revenues each year makes it possible for us to put more energy into seeking out new sources of support,” said Hope Happens Executive Director Dennis O’Brien. “I hope other donors who recognize the importance of fast-tracking cures and believe in our new model of doing translational research will follow the lead of the Philpott family and make multi-year pledges.”