

HOPE HAPPENS

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



Summer 2008 Newsletter

www.hopehappens.org

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the fourth annual evening of **hope**

featured **Anne Akiko Meyers, raised money for research**

More than 250 guests enjoyed cocktails, dinner, a stirring concert and a reception with the artists at the Sheldon Concert Hall on May 14. An additional 50 people purchased concert-only tickets.

"We are delighted to support this magnificent event," said Honorary Chairs of the event Doug and Vicki Hill. "There is an enormous need to translate basic scientific discoveries into treatments and cures that can help people today. We believe that the collaborative work of the Hope Center scientists is our best solution for making that happen."

Jean Hobler, mother of Hope Happens founder Christopher Hobler, Susie Philpott and Ambassador George W. Walker and Carol Walker co-chaired the event. Kathleen Rogers and Carrie Martin co-chaired the Patron Committee.



Photo: Margaret Rambo

Violinist Anne Akiko Meyers and accompanist Peter Henderson enthralled guests.

Support for translational research

"Edward Jones is pleased to remain a Principal Sponsor of the Evening of Hope because we believe this new, collaborative approach has the best chance of rapidly finding cures for neurological disorders that afflict more than 50 million Americans," said Robert Ciapciak, General Partner of the firm. "Hopefully, that day will come soon."

The event raised almost \$160,000 to support cutting-edge research to find cures for neurological disorders such as Alzheimer's disease, cerebral palsy, epilepsy, Huntington's disease, Lou Gehrig's disease (ALS), multiple sclerosis Parkinson's disease, prion diseases, stroke, and traumatic brain and spinal cord injury. Every day 7,650 people are diagnosed with one of these nerve-killing disorders—2½ times as many as are diagnosed with cancer.

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-St. Louis, a Silver Sponsor of the event.

(continued on page 3)



Photo: Margaret Rambo

Paul Reuter, Dale Benz and Charlie Pfeffer enjoyed performing their arrangement of an original Chris Hobler song.

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Dr. Timothy M. Miller, MD, PhD

One hundred guests attended the dedication of the Christopher Wells Hobler Laboratory for ALS Research on February 18, 2008 at the Farrell Learning and Teaching Center. Dean Larry J. Shapiro, Executive Vice Chancellor for Medical Affairs, and Dr. David M. Holtzman, chair of Neurology, were among the speakers who praised Chris's vision and determination to find cures by promoting collaborative, translational research. The lab is yet another step forward in the Hope Center's goal of discovery and translation through cutting-edge, collaborative research.

A portrait of Chris by renowned portrait painter Gilbert Early that will hang outside the lab was also unveiled.

The laboratory will be under the direction of Dr. Timothy M. Miller, MD, PhD, who was recruited from the University of California-San Diego to Washington University to continue his very promising research on finding cures for ALS. Dr. Miller, who completed his MD/PhD at Washington University School of Medicine in 1998, has become one of the nation's foremost researchers on ALS.

Evening of Hope

(continued from page 1)

Event generates awareness, inspires hope

The event helped create awareness about the need for cures and the hope that they can be found through this new model of doing research in a collaborative fashion to translate basic scientific discoveries into new treatments and cures.

"In addition to raising money to fund cutting-edge research, this event raised awareness about the need for cures for neurological disorders and the very real hope we have of finding them," said Steve Maritz, President and CEO of Maritz Inc. "Over the years Maritz has strongly supported this important cause, and we are very pleased to do so once again."

"Goddess of Fire" enthalls guests

The evening starred world renowned violinist Anne Akiko Meyers accompanied by pianist Peter Henderson. Meyers has been described in a recent review as "one of the world's leading soloists, recitalists and chamber musicians, capturing the hearts of audiences and imaginations of composers." She certainly did so at this event, entralling everyone with her passion, technical perfection and wide-ranging repertoire. To learn more about the talented "goddess of fire" and her stunning versatility, visit www.anneakikomeyers.com.

Local artists perform Chris Hobler song

During dinner, guests were treated to the performance of "Don't Ask Why," a song created by Chris Hobler. Before being afflicted with Lou Gehrig's disease in 2001, Hope Happens founder Chris Hobler was a musician. Guitarist Dale Benz and pianist Paul Reuter accompanied singer and guitarist Charlie Pfeffer. Reuter, who organized the performance, is executive director of the Sheldon Concert Hall.

All the artists graciously donated their talents in tribute to the two individuals who inspired this annual fundraising event: Chris Hobler and former St. Louis Symphony Music Director Hans Vonk, who were victims of amyotrophic lateral sclerosis (ALS), commonly known as Lou Gehrig's disease.

The Hope Center

The Hope Center's unique cross-disease research strategy takes advantage of disease-related commonalities and economies of scale to maximize the effect of every donor's philanthropic investment. Hope Center research is founded and funded by Hope Happens, a not-for-profit charity. The Hope Center was formed by a partnership between Hope Happens and Washington University and opened in January 2005. It has now grown to include 484 scientists from 17 departments of the university.

Both partners share Chris Hobler's conviction that fundamental discoveries about one disorder can lead to treatments and cures for other disorders.

Neurology Chief Reports Progress



At the 4th Evening of Hope, Dr. David M. Holtzman reported on some of the progress Hope Center researchers have made toward finding cures that will “improve the lives of people living with neurological disorders.” Here are excerpts from his comments.

In meeting with Chris Hobler several times prior to the collaboration between Hope Happens and the Hope Center began, it was very clear that Chris thought the way that research on neurological disorders was carried out needed to change. He spoke of collaboration, sharing results, defining discreet milestones, and having accountability not unlike what occurs in the business world with companies and their shareholders. Since this is now three years since the opening of the Hope Center, I'd like to provide a snapshot or report card of some of the highlights of the major accomplishments of the Hope Center to everyone here and especially to Chris.

People key

People are everything in an organization, so what people are involved in the Center? Under the leadership of scientific director Dr. Mark Goldberg, deputy director Dr. Anneliese Schaefer, and the Hope Center Steering Committee, we now have 65 Hope Center faculty and over 400 scientist members of the Hope Center who come from 17 different departments involved in our seminars, using the Core facilities, and involved in research projects of the Center.

Results

What have these people done? Well, in terms of direct translation of their findings into people, ideas need to be patented and technology transferred into companies for new diagnostic methods and treatments to be commercialized and used. I'm aware of at least two patents that have come from Hope Center labs that have been licensed to companies. One involves a new treatment for preventing nerve cell degeneration, another a method to determine if new treatments for neurodegeneration are working in humans over a very short time. In addition, a new recruit to the Hope Center, Dr. Timothy M. Miller, MD, PhD, will be starting a novel clinical trial in

patients with certain inherited forms of ALS towards the end of 2008.

In terms of new discoveries offering Hope for the future, a new gene that causes ALS was discovered by Hope Center scientists and published in February of this year, new diagnostic methods for Alzheimer's disease that detect the disease before symptoms start were found, and a new treatment for certain kinds of epilepsy was just reported on. These are just a sampling of what is going on.

Return on investment

Has the investment by Hope Happens in the Hope Center led to greater return on the investment? That is clearly a resounding, “Yes.” I will highlight two accomplishments in particular. The Hope Center spearheaded a proposal to grow and improve translational neuroscience efforts at Washington University. This led to a successful NIH grant application awarded to only four centers nationwide. Our application was the only application funded to a single site and is providing \$12 million over five years. In addition to the NIH, Washington University has provided a significant amount of both financial and other resources to the Hope Center. For example, in the new BJC Institute of Health building being built in the center of the medical school campus, there will be five new interdisciplinary research centers. A component of the Hope Center focusing on a scientific problem called “protein misfolding” will be located in 15,000 square feet of brand new lab space in this new building.

Progress toward cures

There is no question that there are many, many more discoveries to be made to help us to better understand diseases involving neurodegeneration that will be critical in enabling developments of new treatments and cures. To date, I don't know what kind of “grade” Chris Hobler would give us toward accomplishing the Hope Center mission. What I can say is that we are making progress, we have some of the most talented scientists in the world working together, and that everyone at the Hope Center is incredibly committed and will continue to put all their efforts toward fulfilling the Hope Center mission.

Dr. Holtzman's research team has significantly advanced our understanding of the biology of Alzheimer's disease by:

Uncovering mechanisms by which a potential new therapy called “passive immunization” may act as a treatment for Alzheimer's disease. This has led to a large ongoing clinical trial.

Finding biomarkers in spinal fluid that correlate with the presence of Alzheimer's pathology in the brain even prior to dementia. This could help identify healthy people who are candidates for therapies designed to prevent dementia before it starts.

Developing a method of rapidly assessing the formation and clearance of destructive proteins in the human brain. This technique is being utilized to determine if drugs currently in development for Alzheimer's disease and other neurodegenerative diseases are likely to work.

Dr. David M. Holtzman, MD

Chair of the Dept. of Neurology at Washington University School of Medicine, Neurologist-in-Chief at Barnes-Jewish Hospital, and the Andrew and Gretchen Jones Professor, has received numerous awards, including the Potamkin Prize and the MetLife award for his research on Alzheimer's disease.

Dr. Holtzman played a key role in the collaboration between Hope Happens and Washington University to create the Hope Center and provided the leadership to grow it into the powerful source of hope for all of us it is today. Dr. Holtzman serves on the board of directors of Hope Happens and the steering and executive committees of the Hope Center.

Brainstorm - Ladue Chapel Sponsors Information Series



Drs. Bayly, Holtzman, Klein, Miller and Schaefer answer questions from the Ladue Chapel audience.

Ladue Chapel Presbyterian Church teamed up with Hope Happens to sponsor a four-part education series about brain diseases and the current state of research for cures. The series was open to the general public, and 375 people attended the sessions held over four Sundays in June.

Philip V. Bayly, PhD, Mark P. Goldberg, MD, David M. Holtzman, MD, Robyn S. Klein, MD, PhD, Timothy M. Miller, MD, PhD, and Anneliese Schaefer, JD, PhD, discussed current trends and the possibility of breakthroughs for Alzheimer's disease, Lou Gehrig's disease, multiple sclerosis and neuroinflammation, Parkinson's disease, stroke, translational research and traumatic brain and spinal cord injury.

“The Hope Happens story needs to be told far and wide,” said Sherry Delo, chair of the Personal Growth track for Adult Education at Ladue Chapel. “The story has three compelling parts. First, Hope Happens and the Center for Neurological Disorders at Washington University are a result of the vision of Chris Hobler who died of ALS.

“Secondly, it was Chris and his family who immediately understood that the study of orphan diseases needs to be centralized so information about diseases of the brain can be easily shared across various disciplines by researchers and physicians.

“The third part of this never-ending story is the research and the findings of these doctors and researchers. People of all ages are eager to know more about progress made and about ongoing work that could lead to future findings and to cures that will help people.”

After visiting the Hope Center and seeing firsthand the cutting-edge approach to research, Delo concluded that Ladue Chapel parishioners and others needed to hear the message of hope. “Ladue Chapel is full of curious, caring people who want to learn and know more about many topics including progress in healthcare,” she said. “The Brainstorm series and the story of Hope Happens were a perfect fit.”

The result? “It was truly a message of hope,” she said. “Baby Boomers and parents of Baby Boomers who saw polio virtually eradicated through the Salk vaccine understand that research pays off, and these researchers left us hopeful that new treatments and cures will be found for many of these disorders.”

**For a CD of the
Brainstrom series,
call Hope Happens
at 314.289.5660**

Preeminent Scientists Join Executive Committee

The Hope Center has added two widely respected scientists to its Executive Committee, Drs. Floyd E. Bloom, MD, and Thomas A. Woolsey, MD. The Executive Committee is the eight-member governing body of the center responsible for determining policy, direction and the allocation of financial resources. Dr. Bloom is chairman emeritus of the Department of Neuropharmacology at the Scripps Research Institute in California, past president of the American Association for the Advancement of Science, and former editor-in-chief of *Science*. He is founder of Neurome, Inc., and author of 25 books. For more about Dr. Woolsey, see article on page 8.

What is “Translational Research”?

Simply put, it means translating basic scientific discoveries into valid clinical treatments for patients. Historically, the National Institutes of Health (NIH) has funded basic research and clinical trials, to the neglect of translational research. As a result, it takes years and sometimes decades for basic scientific discoveries to make their way to clinical trials with humans.

Typically, scientists with the expertise to make basic scientific discoveries lack the specific skill sets necessary to design the pre-clinical experiments to test whether a discovery can be shaped into an effective therapy. Special—and usually very expensive—facilities are also necessary to support translational research.

In addition to its cutting-edge model of collaboration across disciplines and diseases, the Hope Center is focused on translational research. With support from Hope Happens, it has assembled the necessary core facilities and trained scientists with the expertise to design pre-clinical experiments that might demonstrate evidence of a potential cure so that pharmaceutical companies and the NIH will back clinical trials to test its safety and efficacy.

Burroughs Classmates Honor Chris Hobler

Members of the John Burroughs School class of 1983 made contributions to a special fund in memory of Chris Hobler on what would have been his 42nd birthday on August 27, 2007. The gift was used to purchase a Fujifilm FLA-7000 Image Reader that was displayed at the dedication of the Hobler Lab on February 18, 2008.

Dr. Timothy M. Miller, MD, PhD, Asst. Professor of Neurology at Washington University, was very excited to have this special piece of equipment. "The Image Reader allows us to image and quantify proteins, DNA, RNA, or lipids that have been labeled with either radiation or fluorescence," he said. "Compared to using regular X-ray film, the Image Reader is faster and much more accurate for quantification. Understanding how much individual proteins or RNA have changed in disease models may give important clues to the cause of a particular neurodegenerative disease."

"The class of '83 has always been tightly knit and supportive," said Dr. Tim Philpott who, along with classmate Tom Ruwitch, organized the campaign. "I hoped the class would participate in a special gift on behalf of Chris and was amazed at the tremendous support shown by the class. Chris was a much loved member of our group. His struggle with ALS and his vision for a cure has and always will inspire us."

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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.

Tom Woolsey Joins Hope Team



Dr. Thomas A. Woolsey, MD, recently agreed to serve a three-year term on the Hope Happens Board of Directors. Dr. Woolsey is a Professor of Experimental Neurosurgery and of Experimental Neurology at Washington University. He is the George H. and Ethel R. Bishop Scholar in Neuroscience and author of 75 scientific papers and other

publications on the structure, function and development of the central nervous system and the relation of brain blood supply to these properties.

He will serve on the Advancement Committee of the board and represent Hope Happens on the Executive Committee of the Hope Center. “Dr. Woolsey is a widely respected scientist and educator with a wealth of connections in the community and a passionate commitment to finding cures for neurological disorders,” said board president Jeff Hercules. “We are delighted that he has agreed to join us.”

Multiyear Pledges Expand Capacity

Hope Happens is encouraging donors to consider making multi-year pledges of support. “Knowing that there is a committed stream of revenues each year makes it possible for us to plan effectively and put more energy into seeking new sources of support,” said Hope Happens Executive Director Dennis O’Brien. “Most importantly, it expands our capacity to find cures more rapidly.”

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 is much more efficient for us and effective for the recipient.”

O’Brien agrees. “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.”