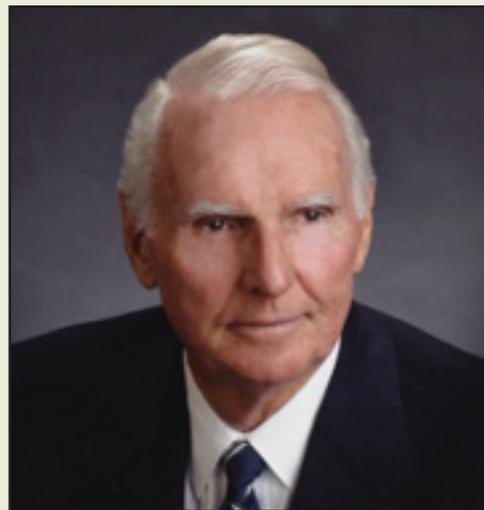


## Jack Taylor Contributes to the Danforth Challenge for Neurological Disorders

On behalf of the entire board of Hope Happens, we are pleased to announce that Jack Taylor, Enterprise Rent-A-Car founder, has made a significant donation to Hope Happens. His gift will be designated in part to the Danforth Challenge at the Hope Center for Neurological Disorders at Washington University School of Medicine and to Hope Happens.

The Danforth Challenge for Neurological Disorders has been established by a generous gift from the Danforth Foundation to support innovative research at the internationally known Hope Center for Neurological Disorders.

The endowment is named for the late Donald Danforth, Jr., a 1955 graduate of the Olin Business School at Washington University, who was an executive vice president of Ralston-Purina, a notable entrepreneur and a trustee of the Danforth Foundation. Danforth was the brother of Washington University's Chancellor Emeritus William H. Danforth, former U.S. Senator John Danforth, and St. Louisan Dorothy Danforth Miller.



*Jack Taylor, founder of Enterprise Rent-A-Car*

The Danforth Challenge will match all endowment gifts for the Hope Center up to a total of \$10 million, providing a rare opportunity to double the impact of the donor's gift. The funds will be used to support innovative and groundbreaking new ideas for research with clear potential to improve diagnosis and treatment of patients with amyotrophic lateral sclerosis (ALS), Alzheimer's disease, Parkinson's disease, stroke, epilepsy, Huntington's disease, multiple sclerosis, cerebral palsy, spinal cord injury and other disorders.



## Jean Hobler Honored by the ALS Association



Jean Hobler, founder and board member of Hope Happens for Neurological Disorders, was one of the honored guests at the ALS 25th Anniversary Gala on Saturday, November 7, 2009 at the Saint Louis Club in Clayton, Missouri. The Gala was sponsored by the ALS Association, St. Louis Regional Chapter and commemorated 25 years of service to ALS patients throughout Eastern Missouri, Central and Southern Illinois...celebrating help and hope to patients and their families living with Lou Gehrig's Disease. Gala co-chairs were Julie and Bob Kindle and Fred and Kristin Kostecki.

Other honored guests included actress, Kate Linder, Hollywood Walk of Fame Recipient for her long standing role on "The Young and the Restless" and celebrity spokesperson for the ALS Association; and the Missouri Foundation for Health, the largest healthcare foundation in the state of Missouri.

For additional information, please contact Gale Ingram, Development Director, (314) 423-7257 ext. 2, or [gingram@alsastl.org](mailto:gingram@alsastl.org).

## John Brightman recognized as an "Ageless-Remarkable St. Louisan"



John Brightman, Hope Happens board member, was recognized with 19 other remarkable seniors, for their incredible contributions at the St. Andrew's Resources for Senior's 7th annual "Ageless" Remarkable St. Louisans gala held on November 1st, 2009 at the Chase Park Plaza Hotel. Wells Fargo Advisors was the event's Presenting Sponsor. The list of honorees included:

Ben Abell	Marie Hatten	Marjorie Smith
Melvin Bahle	Mary Ann Lee	Jack Strosnider
John Brightman	Edwin & Lenore Pepper	Dr. William Tao
Peter Bunce	Anthony Sansone, Sr.	Earl Walker
Fredrick Conrad	William Schicker	George H. Walker, III
Rosemary Davison	Dr. Egon Schwarz	Alexandra Zaharias
Annie Graham	Sydell Shayer	

Presented by St. Andrew's Resources for Seniors and Wells Fargo Advisors, the gala event celebrated the commitment, vivacity and generosity of these individuals and their amazing contributions to the St. Louis community. With varying backgrounds, talents, and vitality that would put most 20-, 30- and 40-year-olds to shame, the honorees are defying the stereotypical idea that individuals fall into "restful retirement" as they grow older.

For additional information, please contact the St. Andrew's Resources for Seniors by calling (314) 726-0111. Proceeds benefited the St. Andrew's Charitable Foundation.

**Hope Happens  
Board of Directors**

- Thomas R. Martin, President
- Russell Viehmann, Vice President
- Bill Hizar, Secretary
- Mary Bettis
- John Brightman
- Lou Chiodini
- Jim Connett
- Christopher Danforth
- Aimee Davis
- Leigh Hobler Gerard
- Jeff Hercules
- Jean Hobler
- Peter Hobler
- David Holtzman, MD
- Marcia Mellitz, MBA
- Tim Philpott, MD
- Thomas A. Woolsey, MD

**Hope Happens  
Board of Advisors**

- Russell Brightman
- Tony Chiodini
- Pete Genovese
- Jen Hobler
- Hal Kroeger
- Flip Maritz
- Paul Wagman
- Carole Wilson

**The Hope Center for  
Neurological Disorders at  
Washington University**

**Director**

Mark Goldberg, MD

**Administrative Director**

Matt Stowe, JD

**Executive Committee**

- Floyd E. Bloom, MD
- Alison Goate, D.Phil.
- Jean Hobler
- David Holtzman, MD
- Thomas R. Martin
- Marcia Mellitz, MBA
- Thomas A. Woolsey, MD

# About Sandy Kaplan

Hope Happens is very pleased to welcome Sandy Kaplan as our Director of Development. Sandy brings great experience and understanding about the work Hope Happens is doing having worked for 20 years at the Barnes-Jewish Hospital Foundation as a Major Gifts Officer.

Over the years, she has had an opportunity to work with some of the neurologists at Washington University School of Medicine such as Dr. Anne Cross, Dr. Joel Perlmutter and Dr. John Morris.



Sandy has been in the fundraising and development field for almost 30 years and most recently worked with Dr. Ira Kodner at the Center for the Study of

Ethics and Human Values at Washington University. As a Development Consultant, she organized and managed a \$10 million endowment campaign for Congregation B'nai Amoona.

She is excited to help Hope Happens and their partnership with the Hope Center and is looking forward to accomplishing the goals that they share.

## How You Can Help Hope Happens

You can help shape the future of devastating neurological disorders by donating to Hope Happens. Your generous donations will allow doctors and scientists to do the research necessary to find cures for neurological disorders such as ALS, Alzheimer's, Multiple Sclerosis, Parkinson's, Epilepsy, Brain and Spinal Cord trauma and Stroke. Please contact Hope Happens to find out how you can make a difference.

Sandy Kaplan  
 Director of Development  
 Hope Happens  
 101 South Hanley Road  
 Suite 1320  
 Clayton, MO 63105  
 314-725-3888  
[sandy@hopehappens.org](mailto:sandy@hopehappens.org)  
[www.hopehappens.org](http://www.hopehappens.org)

# ADVANCING HOPE

## The Danforth Foundation challenge: promise for Hope Center patients and their families

Article by Diane Duke Williams

*EDITORS NOTE: This was an article that appeared in the Summer 2009 issue of the Outlook magazine. Outlook is a magazine published by the Washington University School of Medicine from the Office of Medical Public Affairs. This article showcases the Hope Center for Neurological Disorders and we wanted to share it with our Hope Happens friends.*

About 3,000 Americans are diagnosed with neurological disorders every day. As life expectancy increases, this figure is projected to double in the next 30 years. The current financial and emotional costs of these disorders are staggering. In years to come, such costs will increase exponentially. Hearing a diagnosis of conditions such as Huntington's disease, amyotrophic lateral sclerosis (ALS), stroke or multiple sclerosis (MS) can be devastating for both patients and their families. For many of these diseases, there are limited treatments and no cures.

**"It's very exciting to know there's something as outstanding as the Hope Center in my backyard," says Jessica Spear, 3-year-old Brendon's mom. The two were photographed during a recent visit to St. Louis Children's Hospital. To learn more about Brendon and pediatric stroke, visit [BrendonsSmile.org](http://BrendonsSmile.org).**

The Hope Center for Neurological Disorders, a research center dedicated to fast-tracking the process of finding causes and cures for these and other neurological disorders, is actively working to change that. Its researchers believe that fundamental discoveries made in one disease can lead to more effective treatments and diagnoses in many others.

The Hope Center received a significant boost through a \$10 million gift from the Danforth Foundation, which will create an endowment to support innovative research and will be named for the late Donald Danforth Jr., a 1955 graduate of the Olin Business School at Washington University and executive vice president of Ralston Purina Co.

Now the university and Hope Happens, an initiative begun by Christopher Wells Hobler, who lost his life to ALS in 2005, have committed to raise matching endowed funds of \$10 million by December 2013.

The tremendous excitement of this catalyst for the research effort is best described by patients and their families — those who will directly benefit from its results.

### Helping the youngest patients

When toddler Brendon Spear began making attempts to walk, his mother noticed that he dragged his right foot and favored his left arm.

"It reminded me of someone who had suffered a stroke," recalls Jessica Spear, who had previously cared for stroke patients at a nursing home. "But then I would tell myself, 'Babies don't have strokes.'"

Brendon's pediatrician and a pediatric orthopedist both dismissed Spear's concerns about her son's gait, telling her Brendon would outgrow these problems. He was almost 2 years old when a neurologist determined that he had suffered a stroke in utero and had cerebral palsy as a result.

Brendon, now 3, loves to race cars and chase his cat, Ruthie. But he wears braces on both feet and a splint on his right arm. He also



stutters and becomes frustrated trying to find the words to express what he's thinking.

Since being referred to Bradley L. Schlaggar, MD, PhD, associate professor of pediatric neurology, and beginning therapy, Brendon can run faster, jump higher and climb stairs using alternate feet. His speech also has improved.

"Our goal is to increase awareness of pediatric stroke and encourage much needed research in this area," says Spear. "You feel like you're in a race against time when you have a child with these needs."



Jean Hobler, left, and her daughter, Leigh Hobler Gerard, from Hope Happens meet with Jeffrey D. Milbrandt, MD, PhD, Dean Larry J. Shapiro, MD, Robert H. Baloh, MD, PhD, and Hope Center director Mark P. Goldberg, MD, to learn about the latest advances in neurological research and treatments.

## Ongoing care, support — and optimism

As a 24-year-old newlywed, Carole Wilson was told she had multiple sclerosis (MS), a condition in which the immune system attacks the central nervous system. An avid runner and walker, Wilson had made an appointment with her doctor because she thought a pinched nerve was causing numbness in her left leg.

"I was shocked," Wilson says of her diagnosis. "I asked if I could still have children."

Five years later, Wilson gave birth to a son. She felt fine during her pregnancy, but had her first flare-up when her new baby was just 6 months old.

MS has mainly affected Wilson's legs. When her son was 4 years old, she began using a cane. Today, at 45, she needs a walker for everyday life and uses a wheelchair at the mall or a baseball game.

Wilson came to Washington University years ago after reading an article about neuroimmunologist John L. Trotter, MD. When he died suddenly in 2001, she became a patient of Becky J. Parks, MD, assistant professor of neurology.

"I feel like I'm in the loop and am getting the best care available," says Wilson, who serves on the Hope Center's advisory board. "When I toured the Hope Center, just seeing all the research being done was so exciting." Wilson has met many of the Hope Center physicians, and she's inspired by their dedication.

"I think the Hope Center has exceptional leadership and a great group of doctors," she says. "If anyone can find a link between these neurodegenerative diseases, they can."

## Partnering for a good outcome

In 2007 and 2008, Zoe Cooper participated in clinical trials of the drug Rituxan for the treatment of MS. Before beginning the first trial, she suffered a seizure. She also had experienced numbness, balance problems and trouble driving. An MRI revealed she had 13 lesions on her brain.

Cooper received an IV of Rituxan once a week for one month during the trials. A follow-up MRI after her last treatment showed that the lesions had disappeared.

"It was like living a miracle," says Cooper, a 51-year-old registered nurse who was first diagnosed with MS in 2001. "I'm getting goose bumps just talking about it. I felt like my old self again."

It was Cooper's physician, Anne Cross, MD, professor of neurology, who referred her to the trials. "I can't express how excited and grateful I am that I was in a place with a group of doctors where this was available," Cooper says. "I know if I get sick again, there is something that works for me."

Cooper's dream is that Hope Center researchers will be able to find similarly effective treatments for other patients with neurodegenerative disorders. "I wish," she says, "that other people could have the same results."

## You, too, can offer HOPE

**ANNOUNCING**  
The Danforth Foundation  
Challenge for the Hope Center  
for Neurological Disorders

The Challenge supports the most promising basic and clinical research in neurological disorders. Your support furthers these programs to understand the causes of disease, develop improved treatments and search for lifesaving cures. Only through significant private funding will rapid advances occur.

### Your gift to the Hope Center will:

- Fuel the momentum on fast-breaking research developments by eliminating the lag time in traditional funding mechanisms
- Support evaluation of new drugs and therapies not ready for pharmaceutical company development
- Fund exciting early-stage research too preliminary for government grants
- Provide funding for targeted interdisciplinary research projects

**For more information, please contact:**

Sandy Kaplan - 314-725-3888 - [sandy@hopehappens.org](mailto:sandy@hopehappens.org)

# Meet Your Hope Center Scientist!

*This is the second in the series of newsletter interviews about our Hope Center scientists and the important research that is being conducted at the Hope Center for Neurological Disorders at the Washington University School of Medicine in St. Louis, Missouri. Your donations allow this amazing research to be conducted in hopes of finding cures.*

*Elisa Reeves interviewed Dr. Anne Cross, the Manny and Rosalyn Rosenthal - Dr. John Trotter MS Center Chair in Neuroimmunology and the Director of the Multiple Sclerosis Center at the Washington University School of Medicine, on Monday, September 28, 2009. With her team, Dr. Cross discovered that Rituximab (Rituxan), an already FDA approved drug for Rheumatoid Arthritis, significantly reduces the number of B-Cells in MS patients. This is an exciting discovery and holds much promise for the future of people with MS.*

*For more information about Dr. Cross' research, please visit her website:*

*<http://neuro.wustl.edu/aboutus/facultybiographies/cross.htm>.*

## **How long have you been working with the Hope Center?**

I have been at the Hope Center as long as it has been in existence and have been at Washington University School of Medicine for 18 years. Previously, I was at Albert Einstein College of Medicine in New York.

## **What do you study?**

I primarily work on Multiple Sclerosis (MS), which is a neurodegenerative disease that affects the nerve cells' ability to communicate with each other in the brain and spinal cord. MS is a disease that often hits young people. It actually affects about 1 in 1000 people in the United States and about 1 in 500 in the United Kingdom and Scandinavia.

I chose to work on MS for several reasons. There were no treatments that really altered the long-term course of MS and it was a common disease. As of 1993, we had medications that slowed but did not stop the progression of MS. This has changed the world of MS patients, but it has not stopped the neurodegeneration MS causes. While progression of MS has been slowed, we have no good grasp of what causes MS, how to stop it, or how to reverse it, which would be the ultimate dream.

I also knew three people who had MS by the time I chose to study this disease. I always knew even before I went into medical school that I wanted to do medical research, and I had to decide what to work on. At first, I was going to work on Parkinson's disease, but then I began to admit a lot of patients during my neurology residency who were my age or sometimes younger being diagnosed with MS. There was no treatment, which was very discouraging and disheartening to those people. There was a woman in medical school with me who developed MS, as well as two friends who were residents with me, one in neurology and one in internal medicine. I was particularly close with my colleague in internal medicine. Those are the reasons why I chose to work in this field.

## **What questions are you trying to answer in your work?**

To some degree, it is the complex questions of the cause of neurodegeneration. We are certainly still looking at what causes inflammation and neurodegeneration in MS patients. MS is a little bit odd in the sense that in many people you have a relapsing, remitting course. People will have an attack,

have inflammation and a degree of neurological impairment that may or may not remit partially, totally or not at all. Sometimes when it remits, patients will go almost back to normal. I am very interested in why that happens because if you can understand what causes people to have remission, maybe we could prolong or prevent the onset of the attacks.

## **What is the most interesting project you have worked on?**

One thing that was particularly gratifying for me was that I played an instrumental role in seeing a concept go from the animal model stage up to the human trial stage. In the 1990's, I got interested in B-Cells (a type of white blood cell associated with inflammation), their products, and their roll in the pathogenesis of MS. Dr. Jeri Lyons, a fellow working with me at the time, and I were interested in looking at how B-Cells got into the central nervous system where they don't normal go. We embarked upon looking at mice that lacked B-Cells. We tried to induce EAE, the animal model for MS, in them using certain types of myelin proteins that are used to induce that animal model. We found that the B-Cell deficient mice were resistant to MS. That was really unexpected and very interesting.

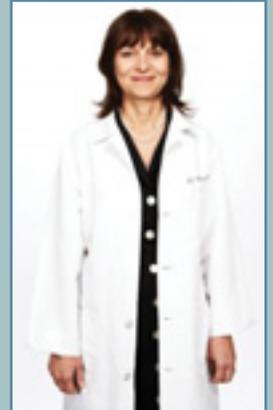
Around 1999, I became aware of the existence of a drug called Rituximab, which is a chimeric monoclonal antibody against B-Cells. It rids the circulation of B-Cells in the human body. However, it is not clear if it gets rid of all B-Cells in every tissue or organ. If we got rid of B-Cells, which is the only thing Rituximab targeted, we might learn more about the pathogenesis of MS.

I learned about Rituximab through a Hope Center physician, Dr. Alan Pestronk and his group. I thought this was an opportunity to help my patients who were helped by the current drugs at the time. In doing so, we might also be able to find a drug to help those patients who were not benefiting from our present medications.

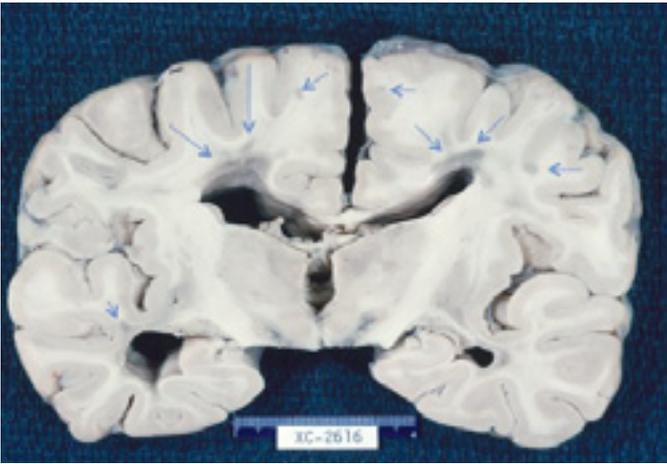
## **About Anne H. Cross, M.D.**

Dr. Cross graduated summa cum laude from the University of South Alabama with a B.S. in chemistry and cum laude from the University of Alabama School of Medicine. She did neurology residency training at the George Washington University, serving as Chief Resident in her final year. Following six years of fellowship training in the Neuroimmunology Branch at the NIH, at Saint Jude Children's Research Hospital, and at Albert Einstein College of Medicine in neuropathology, Dr. Cross was awarded the Harry Weaver Neuroscience Scholar Award of the National Multiple Sclerosis Society in 1990.

Dr. Cross is currently the Manny and Rosalyn Rosenthal - Dr. John Trotter MS Center Chair in Neuroimmunology and serves as the Director of the Multiple Sclerosis Center at the Hope Center for Neurological Disorders at Washington University School of Medicine in St. Louis, Missouri.



*Dr. Anne Cross, M.D.*



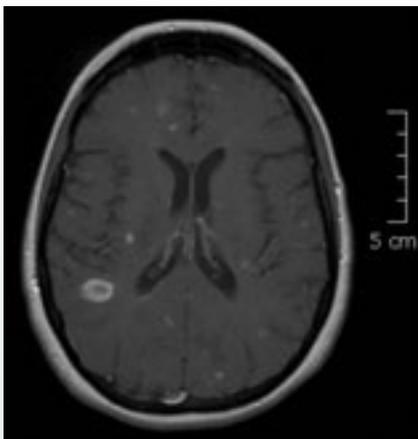
*Coronal slice of the brain of a patient with MS, obtained at autopsy. Arrows point to some of the multiple lesions that are mainly in the white matter.*

It was a long route. First, I had to apply for funding. Eventually, I got most of the funding from the National Multiple Sclerosis Society, partial funding from the National Institute for Health (NIH), and partial funding from Washington University. I was also able to convince Genentech, Inc. who made that molecule, to give it to me free for my study. I wanted to look at 30 patients, and the drug was \$16,000 per treatment for each patient.

Eventually, all of this came together in April of 2002. We enrolled the patients and followed them carefully to make sure nothing bad happened to them and to make sure they got better or at least not any worse. It seemed like a couple of patients got better. We were doing this study using MRI as the blinded outcome, so we would do three MRIs one month apart prior to treatment. Then we would do three after treatment. We had a blinded investigator read all of the MRIs, not knowing what order they were taken in, nor having anything to do with the patient care.

We wanted to enroll 30 patients who were not responding to the present medications and who wanted to be in this trial. It took us until 2008 to enroll all of those patients. It

was not that we didn't have a lot of patients that would fit the bill, but during the interim, other drugs came out that were FDA approved that might help such a patient, and this was an experimental drug. We didn't know what it would do to our patients or what risk there might be. When asking patients about volunteering for this study, we could not suggest that they might get better because that was an unknown. Therefore, the patients had to be truly altruistic to be part of the study and then they had to fit the fairly stringent enrollment criteria for the study as well. However, everyone who entered, did get treatment.



*This is an image of a patient's brain with active multiple sclerosis. You can see several MS lesions that are bright, white areas, including one large ring-enhancing MS lesion.*

We used the MRIs as the blinded outcomes, and we just completed the analysis. I am writing the paper right now, and it was a highly positive study. We had an 88% reduction in advancing active MS lesions, and we had a reduction in relapse rate in the pre-study relapse rate to the on-study relapse rate by about 80%. In the interim, Genentech, Inc. actually did their own multi-center study against a placebo, which we did not take part in, and they also found a very striking reduction. Since then, Genentech, Inc. has manufactured a human form of this monoclonal antibody called Ocrelizumab, which is better because it does not have as many mouse components to it and people will not reject it as easily. Other companies are working on B-cell modulating therapies of different types, so in the long run, these studies will be combined to aim for a new therapy all together. I think it is moving in the right direction. We will probably be involved in some of the future studies as well.

### **What challenge do you face on a daily basis?**

Funding. That is always problematic, especially now because the NIH is not funding very many grant submissions. We have had our last few grant proposals rejected and the National MS Society is not getting many donations. So funding is way down. We have to subsist on what we have now and what we have saved through the years.

### **What do you enjoy most about your job?**

I love my job. I am really happy that I ended up working on MS because there are many aspects of treating this disease. I get to take care of patients, which is enjoyable most of the time. Through the years, I have gotten to know many of my patients, and we have sort of grown up together. Sometimes it can be very frustrating if I cannot help somebody, particularly if I feel bonded to them. I get to teach residents, medical students and fellows, which I enjoy most when it is a one-on-one or one-on-three situation. It is also an opportunity to share my experiences and research with my students.

I do research, which is particularly exciting and gratifying when you are learning things no one else knows yet. Research and writing are satisfying when you are sharing what you have learned about with other people. That is quite a process in the world of research. I write with a team of researchers involved in MS. Then we submit our work to a journal and hope that it gets published. On the other hand, research can be very frustrating for many different reasons. There are three sayings we have in our lab that we say repeatedly. One is, "They call it Research, not Search." Another is "Two steps forward, one step back," which is a common occurrence. The last one, which is one that I have on the wall in my office and have told to my children many times, is by Winston Churchill, "Never, never, never give up." That was the entirety of Churchill's commencement speech to a graduating university class following World War II.

### **Do you have any final thoughts?**

Sometimes people, patients in particular and their families, find it very frustrating when they look at the medical field and the medical research field. It seems like it moves so slowly. I graduated from medical school in 1980 and started in the research world in 1984 following my residency. I get frustrated too. Then I tell myself to look back over that time, those 25 years, and it is clear we have made tremendous progress. Who knows what we are going to have in the next 25 or 50 years. One hundred years ago, we did not even have antibiotics. My daughter would probably be dead because she had so many ear infections when she was a baby. Instead, she is a junior in college. I would just say it is slower than we all would like, but it is moving in the right direction.

hope  
happens  
for neurological disorders

101 S. Hanley, Ste. 1320  
St. Louis, MO 63105

**Return Service Requested**

Non-Profit  
Organization  
U.S. Postage  
**PAID**  
St. Louis, MO  
Permit No. 5653

## *Our Mission*

*To improve the lives of people with neurodegenerative disorders by funding collaborative, translational research that has the potential to fast-track new treatments and cures.*

## **“Generation BIG” Donates Proceeds to Hope Happens for Neurological Disorders**

One of Hope Happens close friends, Tom Ruwitch, has co-written a book, *“Generation BIG – The Rising Tide of Dreams to Action”* with partners Jeffrey Smith and Mark Patterson. The book describes how there’s a rising tide of bold, innovative, and generous (BIG) people who are changing the world. For every book purchased on their website, <http://www.generationBIG.com/hope>, they are donating \$5 to Hope Happens for Neurological Disorders.

*Generation BIG* is more than a collection of inspiring stories. It shows how BIG people inspire, guide and connect. The book offers guidance for anyone who aspires to be BIG. It reveals how individuals and businesses can weave massive generosity into their lives in ways that actually build prosperity, not diminish it.

If you have any questions, please contact Elisa Reeves at Hope Happens, 314-735-3888, or [elisa@hopehappens.org](mailto:elisa@hopehappens.org).

