



# The Ride of His Life



BY PETER GIANOPULOS ✦ PHOTOGRAPHY BY SUSAN MCCONNELL

Having already cycled some 10,000 miles across the United States to raise funds and awareness for ALS, cancer and hospice care, Bob Lee of Barrington will take to the open road again this fall, with the ambitious goal of raising \$1 million. And although his “Ride for 3 Reasons” may seem like an individual effort — one man alone on his bicycle — the reality is far more complex. It’s a story of cooperation across the United States and the world that brings together dedicated researchers, donors, and community volunteers with a spirit of hope and collaboration.



**Bob Lee and his family enjoy a bike ride through Citizens Park in Barrington.**  
**IN FRONT, FROM LEFT: Kyle Horak, Bob Lee, Maggie Horak and Michael Horak.**  
**IN BACK, FROM LEFT: Tom Horak, Anne Lee, Ryan Horak and the Lee's daughter, Laura Horak.**



THIS COMING SEPTEMBER, 70-YEAR-OLD BARRINGTON RESIDENT BOB LEE WILL GET ON HIS BIKE — a 30-speed Americano from Co-Motion Cycles — in Vancouver, Canada, and begin his journey down the West Coast of the United States for some 2,000 miles, until he peddles his way straight across the border into Mexico.

If his previous trips — a 3,254-mile jaunt in 2001 from San Diego to Jacksonville, Fla., and a whopper of a 6,500-mile ride up the East Coast and along the northern border of the United States in 2007 — are any indication, he will pack light. A computer to blog with. A camera to take photos with. A cell phone for communications. A toothbrush. A few changes of clothes. A tent. A lucky charm (a guardian angel hospice pin) and, of course, a bag of chocolate chip cookies from his wife, Anne, who bakes a darn good cookie.

When you've committed yourself, as Bob Lee has, to biking the perimeter of the United States to raise money for charity — for ALS and cancer research and hospice care — you don't save too much room for souvenirs. You don't return home bearing little key chains from California or refrigerator magnets from some outpost in Maine. You bring what you need. Nothing more, nothing less.

What you do come back with are “carry-ons” that are unencumbering and imperishable: memories to share and stories of goodness that you find along the way.

“Most people ask me, ‘Bob, aren't you scared? Aren't you worried you're

going to run into bad people?’ The truth is, I've ridden 10,000 miles and haven't had a bad encounter with a single soul,” Lee says. “It's been just the opposite. People roll down their car windows and say, ‘Gee, didn't I see you last night on TV?’ and hand me money for the charities. I've met people who within five minutes have offered me a bed for the night. It's been amazing. It's proof that there's a world of goodness out there if you only look for it.”

Ostensibly, Bob Lee may be making this, his third solo bike ride — through three countries, for three charities, with the goal of inspiring 3,000 donors —because he's set the lofty goal of raising \$1 million to be divided equally between the three charities. His track record precedes him in terms of achieving his goal. In 2001, he raised \$89,000. In 2007, he more than quadrupled it by raising \$390,000. And now that he's recruited special “Pacesetter” donors (who will match each dollar of individual contributions with two additional dollars out of a special Pacesetter Challenge Pledge Fund), he may, with enough support, actually achieve his mission.

But if his two previous journeys taught him anything, Lee says, it's that stories have a special currency all of their own. Dollars may lead to cures, but stories breed awareness. It's these stories — the ones he collected and the ones he shared — that have turned what began as an individual quest into a vast collaborative effort, binding together followers, donors, researchers and volunteers from over 42 states and seven countries.





**Bob Lee crosses the Continental Divide in Montana near Glacier National Park in a previous Ride For 3 Reasons. According to Lee, “Everything was downhill from there to the East Coast.”**

### **A spirit of collaboration**

The journey always begins at the same place: at home, with his wife, Anne, whose life passion, he says, is to help other people. It's Anne who supplies the motivation, the ideas, the confidence, without which, Lee says, none of this would be possible.

From there, a spirit of collaboration spreads out far and wide into the community of Barrington, with great help from daughter Laura's campaigning, where Lee has seen everything from children breaking their piggy banks to give a few dollars to 60 volunteers who came forward to help in any way they could. This generous spirit has spread to families and organizations, and ultimately to special "Pacesetter donors" who have agreed to pledge somewhere between \$10,000 and \$100,000 each into a special matching fund. "The Pacesetters are truly setting the pace of this ride," says Lee.

It may be a solo ride, but it's an international effort. In Omaha, Jim Langdon, an associate in the window covering industry, helped manage his blogs and website, [www.3reasons.org](http://www.3reasons.org). In the states that Lee has visited, there have been families who have not only welcomed him in for an evening of rest but also strangers who performed random acts of kindness that kept Lee pedaling.

A man in Statesboro, Ga., found Bob's bike on the highway when it accidentally slid out of the back of a pickup truck when he was en-route to a bike

store for repair. Then there was that waitress — the unforgettable waitress — in Oberlin, La., who had to work two jobs to cover the cost of her ailing husband's medications, the one who reached into her purse and handed Bob \$40 because she, too, believed in the causes.

And then, believe it or not, this spirit of goodness expanded further to as far away as New Zealand, where a man read about Bob's travels and emailed to say, "How can I help?"

"I think these are small examples," Lee says, "of wonderful people coming together to make a difference. We are making a difference in more people's lives than we will actually know. I truly believe that. We may not specifically know the direct impact of our research dollars, but I do know these monies will have a lasting effect for generations to come."

Lee's own mission began in his late 50s during a successful career in corporate America. His life was greatly impacted and "redirected" by a small book, *Tuesdays with Morrie* by Mitch Albom. This book not only taught Lee about the devastating disease of ALS, a mysterious fatal disease of the nerve and brain cells that lead to paralysis and death, but also motivated Lee with a message to give back and pay it forward. Another influential book was *Halftime* by Bob Buford. This book taught Lee to look beyond success and seek significance in his life.

What story, he wondered, could he tell that would impact others in the way that these two stories touched him? What story would inspire people to discover their own passions? What story would hold, at its core, significance and impact?

### Finding his pedal power

Bob Lee doesn't consider himself a biker in the traditional sense. He prefers the term "peddler;" he says he has a message "to peddle" – a goal to reach, and diseases to conquer.

"I would not be out riding across our country," says Lee "if it weren't for these charities. This is a purpose-driven ride. Add up the three rides together, and I will have been away from home for 10 months. That's a long time to leave a wonderful wife and family and a very comfortable community."

Bob does acknowledge that there's no better way to see the country than from the seat of a bicycle, which not only slows you down to the point where all of your senses are fully engaged, but also transforms the way people perceive you.

There's a great difference, he says, between how people approach a man sitting in a car and a man astride a bike. Physically, there's no barrier between you and the other person. No window. No car door. No humming engine. It invites, Lee says, perfect strangers to trust you — to talk to you — with an ease and candor that no other form of transportation allows.

So when Bob pulls up on his bike — with the words ALS and cancer and hospice emblazoned on his panniers — something almost magical happens. People come up and start talking, sharing their own experiences with friends and family who are facing cancer, ALS, or end-of-life care decisions.

It is always an even exchange, a collaboration in the oldest sense of the word. A bartering of empathy and ideas. Both Bob Lee and his wife, Anne, are cancer survivors. It was in 1998 that Lee turned to hospice care in Pennsylvania to help his mother come to peace with her death. And there are stories Bob carries with him about ALS.

He began his first "Ride" 11 years ago carrying a handwritten note with 125 names of people who were battling (or lost the battle with) ALS. Now



Fred Griffith of WKYC-TV's "Good Company" interviews Bob Lee during his stop in Cleveland. They are joined by NBA Basketball legend Campy Russell of the Cleveland Cavaliers, a sponsor of the 2007 Ride For 3 Reasons.

there are too many names for one slip of paper. Lee, who became a member of the Les Turner ALS Foundation Board of Directors after his first ride, says he won't stop until he is able to put an asterisk next to some of those names with the appendage, "ALS survivor."

"The people fighting cancer and ALS, the hospice nurses, and all of the people who are collaborating with me on these rides — they are the ones who give me pedal power," says Lee. "It might be a tough day cycling over the Rocky Mountains, but anyone with ALS would trade my toughest day for any of their days. I know I have it easy in comparison."



Dr. Teepu Siddique's recent research breakthrough follows more than two decades of dedicated effort. He is the director of the Les Turner ALS research lab at the Northwestern University Feinberg School of Medicine. Below: Dr. Siddique's ALS research breakthrough announced in the summer of 2011 was news that rapidly traveled the world.







**Dr. Steven Rosen, Sarah Bealles, Bob Lee and Dr. Jack Kessler gather outside of the Northwestern University Feinberg School of Medicine in downtown Chicago.**

Lee, who handles the expenses of the trip himself, donates 100 percent of the proceeds directly to cancer and ALS research, as well as to the National Hospice Foundation which will redirect much of the funds back to a pilot program at Hospice and Palliative Care of Northeastern Illinois designated to help people properly document their end-of-life care wishes. Collaboration between these three organizations is vitally important and necessary for the success of this endeavor.

Lee has made great efforts to find researchers who are committed to breaking down the walls that often compartmentalize medicine into different fields. He personally visits with some of the researchers who benefit from his rides for updates and discussions, validating the power of cooperation that permeates his efforts.

“It is important to donors to know that their donations have made a difference, to know that their money is allowing world-renowned researchers to do work they otherwise might not have the money to do,” Lee says. “And to understand that breakthroughs have occurred because of their efforts.”

In addition to funds raised for the American Cancer Society, proceeds from the ride that go to the Les Turner ALS Foundation have directly fueled critical work at Northwestern University Feinberg School of Medicine. Dr. Teepu Siddique, for example, has recently uncovered what may prove to be one of the major finds in the history of ALS research: the faulty protein pathway that leads to ALS (see ALS sidebar).

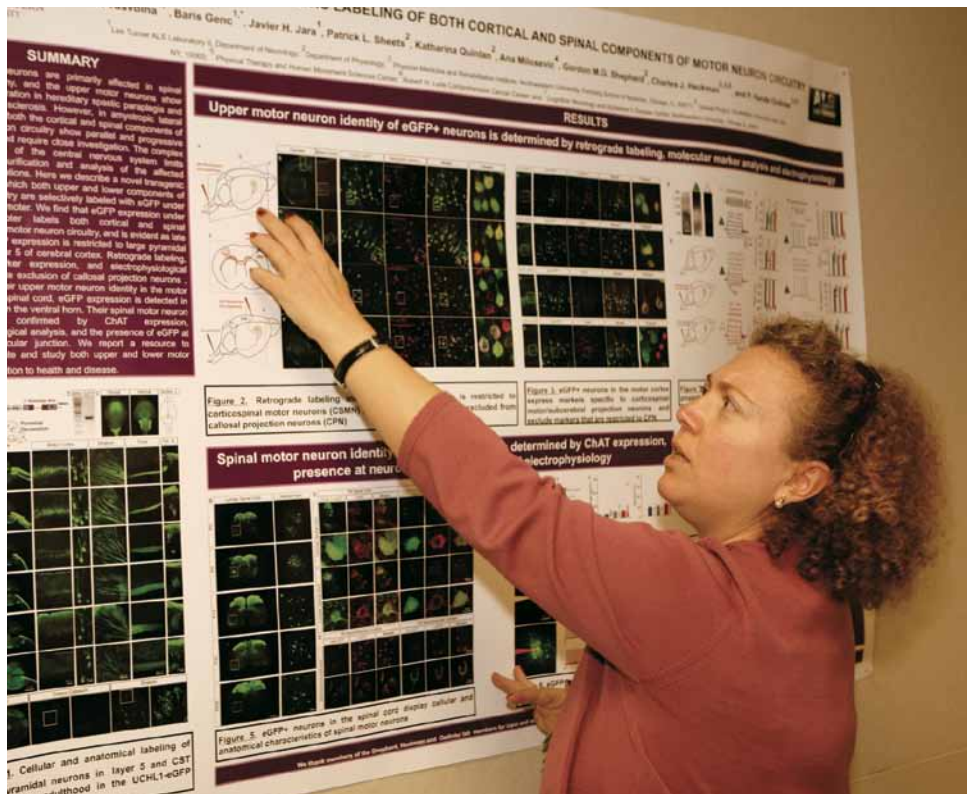
Dr. Hande Ozdinler has mirrored this spirit of collaboration, with what she calls her “friends in the cancer field,” in hopes of better understanding the extrinsic and intrinsic factors that are involved in the degeneration of motor neurons in the brain. In effect, her research is fusing together knowledge of brain trauma, cancer, and ALS for the greater good of all.

Dr. Jack Kessler, director of neurology at Feinberg, whose focus is on regenerative medicine — that is, fixing the damage done by diseases of the nervous system — credits individual donations from foundations and charitable souls with not only fueling the experimental research that leads to the most novel treatments, but also helping to fund some of the most exciting findings in his lab.

### **Measurable impact**

For this ride, Bob and his team of volunteers are attempting to create two real-time innovative initiatives. The first is a version of a “where in the world is Bob Lee” GPS feed, where donors can track Lee during his journey. Unlike previous rides, during which Lee biked at his own pace, this ride will be more carefully planned, with Lee arriving at specific cities at specific times for fundraising events, which he envisions will be casual affairs where people can simply congregate and exchange stories.

It is Lee’s belief in the power of storytelling that is fueling the second key innovation of his website: the development of an “impact wall” on which people from around the world can tell the stories of their own struggles with



Microscopic images of nerves are one of the many interesting sights found inside the Les Turner ALS research lab.


LEFT: Dr. Hande Ozdinler is the director of the Les Turner ALS Laboratory II at Northwestern University.

cancer, ALS and end-of-life care issues. Although Lee has documented his past rides — and the adventures with many people he is met along the way — in his blogs, he sees this “impact wall” as an opportunity for people to honor and remember those who are fighting or have lost their battles with cancer and ALS.

The “impact wall” was inspired by many people, including Andrew Fleeson, an ALS champion whom he met while riding through Scottsdale, Ariz., in 2001 during his first ride. Immediately following that ride, Lee flew directly to Washington D.C. to attend an ALS Advocacy Conference. Fleeson was confined to a wheelchair with very little mobility. Late one evening, Fleeson asked Bob to wheel him to his room to help him prepare for bed. “I realized something that I had always known but hadn’t experienced,” says Lee. “When I helped lift him into bed, he couldn’t pull up the sheet, couldn’t get up to go to the bathroom, basically couldn’t move a muscle.” Andrew lived with ALS for 20 years and was the longest survivor Lee had known. Andrew died in 2011. “He had a great impact on my life as an example of how to face this challenge with a positive attitude and to live each day of one’s life.” Lee says.

It’s people’s stories like these that have given Lee the courage and motivation to ask for sizable donations, which he says would have been a great challenge in the past. “I have met some of the most generous, warmhearted and caring people through this fundraising process. What a pleasure and honor it is for me to meet with so many people who truly want to make a positive impact for all mankind.” As of this writing, there are 23 Pacesetters who have established a Pacesetter Challenge Pledge Fund that will provide two additional dollars for every dollar donated. Lee’s message is to donate now

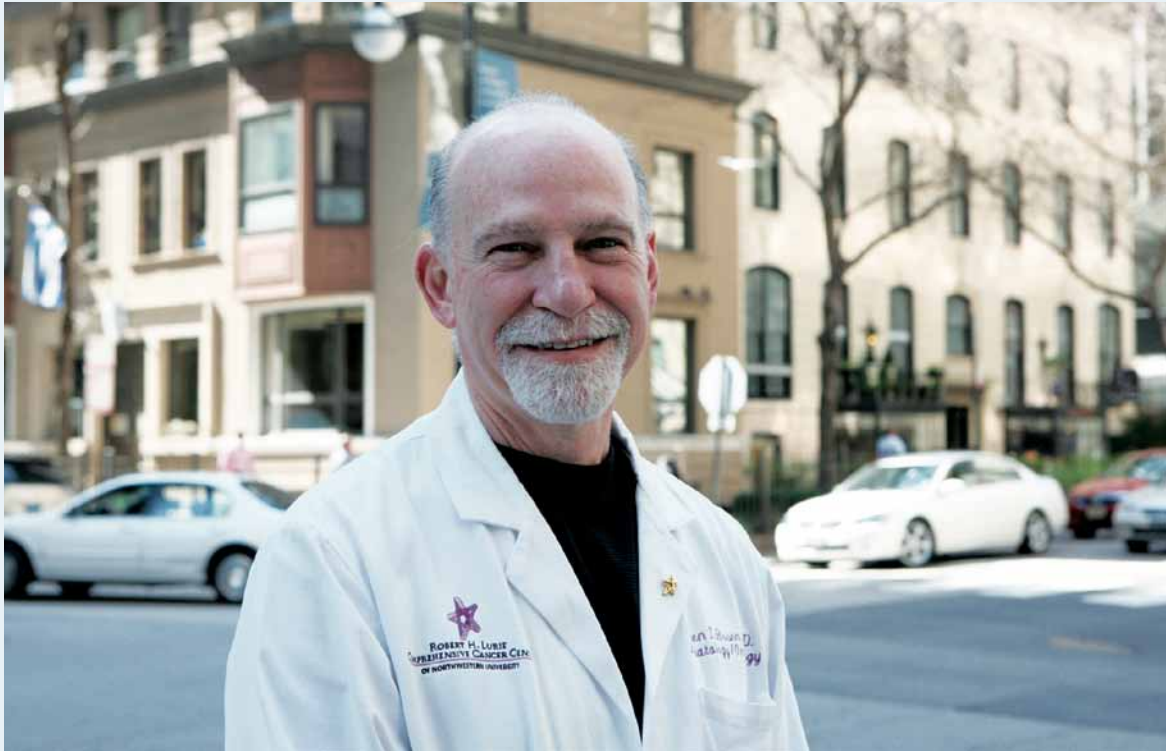
to triple your donation while there are matching funds available. “Initially, I set the goal to raise \$600,000 during this third ride,” said Lee. “As support and encouragement increased, I accepted the challenge to increase the fundraising goal to \$1 million. I became passionate about my purpose to convince people of how critical a moment this is, how now, even during difficult economic times, is a moment when we can and need to make a difference.”

To offer further credence to the belief that “the time is now,” Bob has another experience to share from a previous ride. It’s a story about an orange that was given to him at a fruit stand in Yulee, Fla. Bob says he was so touched by the special gesture, as well as by the prospect of its sweetness, that he decided to save the orange for another day. Although he would think about this orange, he never convinced himself to eat it, waiting for just the “right” moment. Eventually, it was forgotten. One afternoon as Bob rifled through his things, he found that this once beautiful orange was now practically petrified. “I carried this orange hundreds and hundreds of miles,” Lee says, “waiting for the perfect time to enjoy its sweetness. I waited too long. That taught me a lesson. You shouldn’t wait too long and miss out on a good opportunity. Procrastination is the thief of time. There is a right time for everything, and the right time to get involved with the ride is now!” 

To make donations or volunteer to assist in Bob Lee’s ride, visit [www.3reasons.org](http://www.3reasons.org).

*Peter Gianopoulos is a managing editor for Quintessential Media Group.*





**Dr. Steven Rosen is the director of the Robert H. Lurie Comprehensive Cancer Center at Northwestern University.**

**P**AY IT FORWARD. THAT'S BEEN the underlying philosophy behind all of Bob Lee's rides. Do something good. And maybe others — donors, volunteers, organizations and other individuals — might do the same.

After all, both Lee and his wife, Anne, are cancer survivors. They've been on the other side of the equation — the ones waiting, nervously, in doctor's offices for test results. The ones undergoing treatments. The ones who've had to lean on the efforts of previous fundraisers.

"If someone hadn't gone for a ride or did a run or a fundraiser or golf outing or wrote checks, I might not have the opportunity to be out riding today," Lee says. "So this is our opportunity, everyone's opportunity, to make a difference. Hopefully, our generation and the next generations coming forward can have a world that is cancer free."

Which is why he chose the American Cancer Society to receive one-third of the proceeds from the ride. Because, as ACS Vice President Rita Forden says, "Most major advancements in cancer treatments have come about with some help from the American Cancer Society."

The society's research funds know no bounds. Headquartered in Atlanta, Ga., the ACS has 12

## American Cancer Society

THE ROBERT H. LURIE  
COMPREHENSIVE CANCER CENTER  
AT NORTHWESTERN

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chartered divisions, with more than 900 local offices nationwide and has an impact in more than 5,100 communities. One of its maxims, which Bob Lee finds especially prescient, is its tagline, "The official sponsor of birthdays." Part of this is achieved through its funding of early diagnosis, education and community programs for those battling cancer, but it also has a legacy of committing its funds to help researchers work on new and influential treatments.

One need look no further than Northwestern, where, early in his career, Dr. Steven Rosen, the director of the Robert H. Lurie Comprehensive Cancer Center of Northwestern University, received funding from ACS. And although he'll admit that researchers have achieved "astounding advances in the past 20 years in our basic understanding of cancer ... significant challenges remain."

Dr. Rosen predicts that in the next decade, cancer will be the most common cause of death, even with these advances in place. But it's also undeniable that ACS and individual donors have led to breakthroughs in our understanding of cancer cells and why they divide and spread throughout the body.

What is critical, say researchers, is not only National Institute of Health grants, which help speed already established techniques and ideas to the market, but also individual donations from organizations that allow researchers to work on more novel and experimental approaches — studies that show promise but demand more time and evidence before being sent to the NIH for funding.

"Public funding is a critical issue," says Dr. Rosen. "Public funding has been flat for many years now. It still is significant, but is not enough to accomplish our goals. Philanthropy is a critical component for advancing our research. It allows us to think and work creatively, outside the box."

For more information, visit the American Cancer Society at [www.cancer.org](http://www.cancer.org) or call 800-227-2345.



**Sarah Bealles is the CEO of Hospice & Palliative Care of Northeastern Illinois, located in Barrington.**

**B**OB LEE IS WELL AWARE OF HOW difficult it is for any family, even the most open and courageous, to talk about “end-of-life decisions.” It’s a topic easily avoided, a discussion that inevitably brings up words we’d rather not use around the kitchen table: death and loss, hospitals and hospice, pain and peace. But he contends, from his own experience dealing with the loss of his mother in 1998, that they are topics we should all be addressing, every single one of us, not only with the ones we love but for ourselves as well.

One third of the donations to Lee’s ride will be given to the National Hospice Foundation in hopes of inspiring a dialogue about the importance of advance care planning and end-of-life hospice care, two increasingly integral parts of the health care continuum.

In 2010, more than 1.58 million patients were served by more than 4,000 hospice providers, a remarkable step forward from hospice’s humble beginnings in the 1970s as a simple grassroots movement. And yet there is much work to be done in increasing awareness of hospice’s achievements. Studies show that people who receive hospice care tend to live longer with a higher quality of life

## **National Hospice Foundation**

### **HOSPICE & PALLIATIVE CARE OF NORTHEASTERN ILLINOIS**

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as well as reduce health care costs by more than \$2,300 per person. Rates of depression lower and, most importantly, loved ones are often able to live out their final days at home instead of a hospital.

“People want to be at home, surrounded by their loved ones,” says Sarah Bealles, chief executive officer of Hospice & Palliative Care of Northeastern Illinois. “They want peace and comfort. They want awareness and the ability to interact. They do not want to be a burden, and they want to retain their independence. Hospice care can help people achieve these goals.”

It’s a collaborative effort, a coming together of family, caregivers and the patient’s attending physicians in hopes of creating, in Bealles words, “a rich experience, coordinated service delivery, and the best of possible outcomes.” But in order to reach those outcomes it is often critical for in-

dividuals to draft advance care planning directives, a series of instructions for how you (or your loved one) would like to be cared for in the event of a life-threatening disease or hospital stay.

It’s a deeply personal document, says Lee. It’s based on one’s values, wishes and beliefs, but it’s also a document that can reduce the pain and frustration in a moment of crisis. It’s a document that says, “These are my wishes.” Lee believes in it so deeply, in fact, that a major portion of his contributions will return to Hospice & Palliative Care of Northeastern Illinois to create a pilot program designed to help encourage residents in and around Barrington to set up their own living wills and advanced care directives, while learning about the nurturing effects of hospice.

“Our goal,” says Bealles, “is for our patients and families to have the best day they can today, however they define that. When you give people more good days, they have good lives.”

For more information, visit Hospice & Palliative Care of Northeast Illinois at [hospiceanswers.org](http://hospiceanswers.org) or by calling 224-770-2489.





**Dr. Jack Kessler, who oversees the ALS research teams, is the director of neurology at the Feinberg School of Medicine.**

THE GOAL HAS ALWAYS BEEN the same for Bob Lee. For the last 11 years, he's committed himself to biking across the United States in hopes that one day a new phrase — a single breathtaking phrase — will soon enter our vocabulary. And that phrase is, "ALS survivor."

An estimated 350,000 people suffer from amyotrophic lateral sclerosis (ALS), a crippling neurological disease that leads to muscular degeneration and paralysis. Roughly 50 percent of ALS sufferers succumb to the diseases in just three years. Although famous names such as Lou Gehrig, Stephen Hawking and Morrie Schwartz (of the book, *Tuesdays with Morrie*) have increased our awareness of ALS, the underlying disease process that leads to paralysis has remained one of the unsolved mysteries in the field of neurology.

But in the summer of 2011, thanks in part to funding from the Les Turner Foundation, came what can only be called a major medical breakthrough. In a research lab at Northwestern's Feinberg School of Medicine, one of the labs directly funded by Bob Lee's cycling efforts, Dr. Teepu Siddique, a Les Turner ALS Foundation/Herbert C. Wenske Foundation professor, and his team of researchers found what they believe is the pathological process that underlies ALS and other neurodegenerative disorders: damaged proteins, called ubiquitin2 and P62 (SQSTM1), which are re-

## The Les Turner ALS Foundation at Northwestern

sponsible for the management of cellular recycling machinery, i.e. they help recycle other proteins in the neurons of spinal cord and brain. In turn, these "non-recycled" proteins accumulate into clumps, effectively preventing the nervous system from being able to carry messages to the body's muscular system. Future treatments will rest on correction of these pathways.

Speaking in his lab at Northwestern, Dr. Siddique says that this is a critical moment for ALS research, as the promise of new findings competes with the difficulty of raising funds during the economic downturn, but there is great hope.

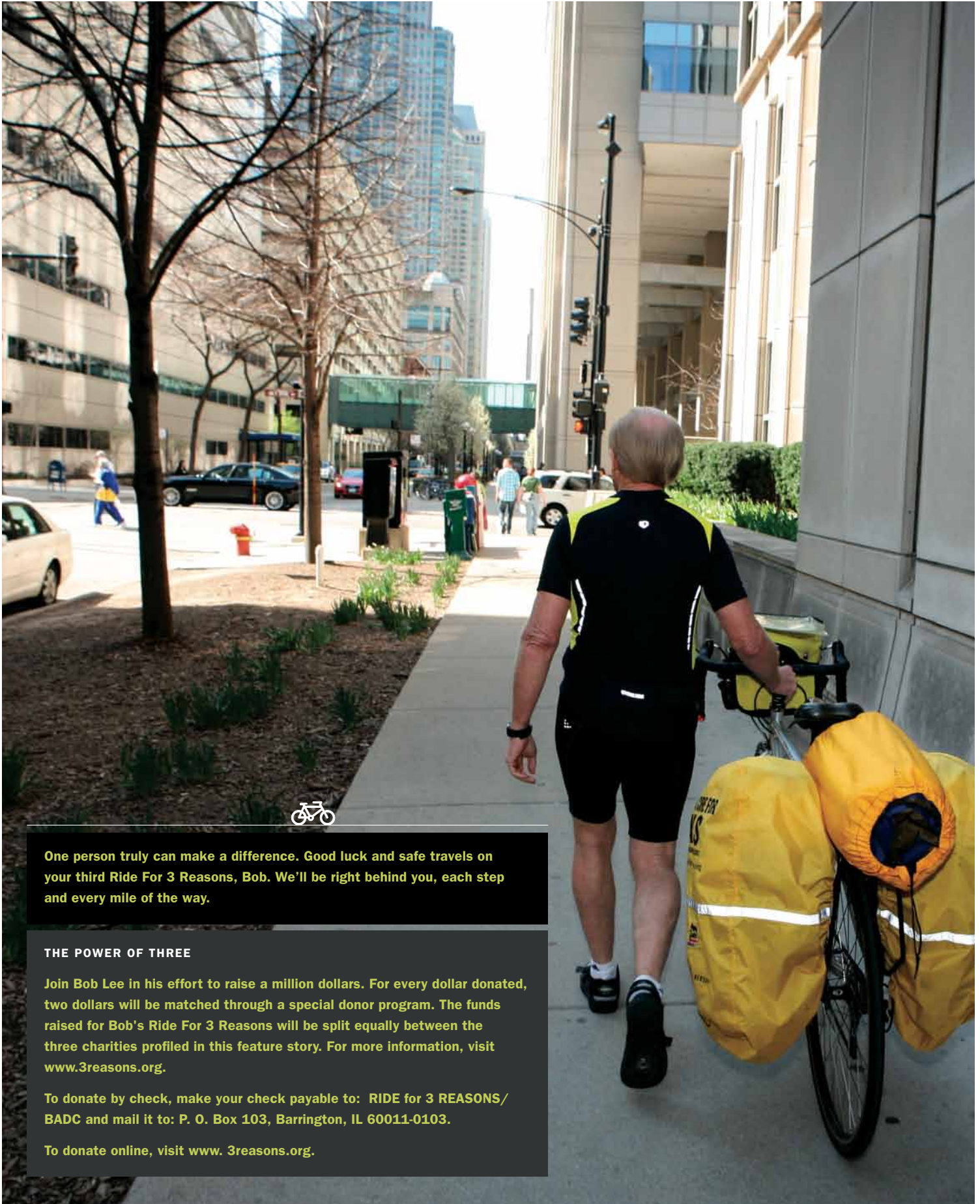
Part of the reason for his optimism lies in the fact that the Les Turner ALS Foundation has worked hard to fund researchers who believe in collaboration instead of compartmentalization, researchers such as Dr. P. Hande Ozdinler, director of Les Turner ALS Laboratory II at Northwestern University, who has made great strides by fusing research in cancer, brain trauma and neurology to understand, on a cellular level, how motor neurons become vulnerable in diseases such as ALS.

"(These funds) do something very important," says Dr. Ozdinler. "They allow you to be innovative and force you to be collaborative because you know that the money you receive was made possible through a collaborative act; you know deep in your heart that you cannot say, 'It's mine.' When you receive a gift from individuals who have run an extra mile to bring you that money and who have swum long distances to bring you that money, you do not have the luxury to be selfish."

Proceeds from Bob Lee's ride are sent directly to the Les Turner ALS Foundation, which was created in 1977 by the friends and family of Chicago area businessman Les Turner in hopes of offering knowledge and research about the disease. The foundation now serves more than 90 percent of the ALS population in the greater Chicago area. Its affiliation with Northwestern means that every donation made to Lee's ride goes directly toward research in labs such as the ones run by Dr. Siddique and Dr. Ozdinler.

"There is no single neuron that functions alone," says Dr. Ozdinler. "The brain is a big (system of neurons) and to be able to understand it, we need to join forces and we need to work together. I see Bob Lee's ride as the spark we need to start the big fire of collaborative enlightenment."

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



One person truly can make a difference. Good luck and safe travels on your third Ride For 3 Reasons, Bob. We'll be right behind you, each step and every mile of the way.

**THE POWER OF THREE**

Join Bob Lee in his effort to raise a million dollars. For every dollar donated, two dollars will be matched through a special donor program. The funds raised for Bob's Ride For 3 Reasons will be split equally between the three charities profiled in this feature story. For more information, visit [www.3reasons.org](http://www.3reasons.org).

To donate by check, make your check payable to: RIDE for 3 REASONS/ BADC and mail it to: P. O. Box 103, Barrington, IL 60011-0103.

To donate online, visit [www.3reasons.org](http://www.3reasons.org).