

# Breathe Bulletin



A Quarterly Newsletter of the  
Pulmonary Fibrosis Foundation  
Volume 6 Issue 3 - October 2006



## *President's Message*

The one haunting frustration of my life is that, after thirty-five years of research on pulmonary fibrosis, we still do not have an effective treatment for the disease. Forty thousand of us continue to die every year. However, on the positive side, we appear to be making significant progress in understanding the causes of pulmonary fibrosis. While there continues to be some disagreement amongst the major researchers, there is one area that more and more researchers are beginning to feel is the major culprit. They believe a gene or genes are responsible for the development of the disease. This discovery has been made possible through the mapping and greater understanding of the human genome and the development of the micro-array system of examining the genetic structure. The micro-array system allows the scientist to study thousands of genes simultaneously as opposed to studying them one at a time.

Dr. Naftali Kaminski of the University of Pittsburgh has isolated a gene which he feels contributes to the development of pulmonary fibrosis. In addition to the University of Pittsburgh, Duke University has been working on familial pulmonary fibrosis for many years and has narrowed down the 30,000 human genes to eight possible contributors. Also, the University of Helsinki Hospital has identified a gene that they believe is a contributing factor in the development of pulmonary fibrosis (see article on page 4). Other research has found that mutations in the proteins, the building blocks of genetic structure, of certain genes cause the disease.

It is quite clear that the key to finding a cure is closely tied to a greater understanding of the disease. We are in the process of setting up a Pulmonary Fibrosis Foundation Center of Excellence at the University of Chicago. The cost of this research program will be \$1,000,000 over a three year period. The research will be conducted at the Pritzker School of Medicine laboratories under the supervision of Dr. Joseph Garcia, Chairman of the Medical School. Other Universities that will be partnering in this program include Northwestern University's Feinberg School of Medicine, the University of Illinois College of Medicine, and, potentially, Loyola University's Stritch School of Medicine.

It is our fondest dream that Centers of Excellence, based upon this model, can be established across the United States. I firmly believe that this level of research is required to find a cure for pulmonary fibrosis. There are no shortcuts to success, and we rely on your support to turn this dream into a reality.

**Michael Rosenzweig, Ph.D., President and CEO**

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## Knieval Family Jumps Into Action Against Pulmonary Fibrosis

The Pulmonary Fibrosis Foundation has had an exciting summer thanks to a newly formed relationship with the legendary daredevil, Evel Knieval, and his family. In June 2006, Evel, who has been living with pulmonary fibrosis for several years, agreed to support the Foundation in any way he could. The Knieval family quickly rallied behind his commitment and has kept the Foundation energized all summer.

Evel's granddaughter, Krysten Knieval, has been the driving force behind the awareness and fundraising efforts of the family. Her idea centered on the creation of pulmonary fibrosis bracelets similar to the "Live Strong" bracelets developed by Lance Armstrong. Her design featured a red, white, and blue bracelet with the slogan "Live Life Full Throttle" in honor her grandfather. The bracelets were debuted at the 5th Annual Evel Knieval Days held in Butte, MT, a festival established to honor the legend in his hometown. Krysten and her family then took to the streets to promote the bracelets, which bracelets also display our website and "Evel Knieval Days 2006."

"I have decided to become involved

with the Pulmonary Fibrosis Foundation because I have seen my grandfather suffer from this disease for several years," says Krysten. "I didn't know much about pulmonary fibrosis except that it was robbing my grandfather of his oxygen supply and, more importantly, his life. I knew I had to do something to educate the public about the disease and also find a way to honor my



*Alicia Knieval Vincent, Evel Knieval, and Krysten Knieval (Photo courtesy of The Montana Standard.)*

grandfather's struggle."

The tremendous success of the bracelets (over 15,000 have sold since their debut on July 27, 2006) has led to Krysten joining the Foundation staff as Event Coordinator. In this position, she will guide and assist dedicated volunteers who offer their time to host fundraising events of their own.

Krysten is not the only Knieval to take on a permanent position with the Foundation. Evel has accepted an invitation to join the Pulmonary Fibrosis Foundation Board of Directors, where he will have the opportunity to provide guidance to the Foundation regarding new initiatives, programs and the overall direction of the organization.

"My grandfather and I are both extremely honored to be involved with the Pulmonary Fibrosis Foundation," says Krysten. "My mission now is to help the Foundation raise funds to find treatments and a cure for this terrible disease."

"Live Life Full Throttle" bracelets are still available from the Pulmonary Fibrosis Foundation for \$3 per bracelet (price includes shipping). Those interested in ordering bracelets should mail payment (no cash please) to The Pulmonary Fibrosis Foundation, 1332 N. Halsted Street, Suite 201, Chicago, IL 60622. Please be sure to include the shipping address and number of bracelets desired.

### Foundation Staff

Michael Rosenzweig, Ph.D.  
*President and CEO*

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*Executive Assistant and Patient Advocate*

Abigail McGlothen  
*Communication Director*

Krysten Knieval  
*Event Coordinator*

Myrrick Liontonia  
*Administrative Assistant*

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## The Devastation of 9/11 Continues

This fall marked the five year anniversary of the September 11th terrorist attacks on the World Trade Center in New York City. As our nation reflected on the day that has forever changed our perceptions of security, the reports paying homage to those individuals whose lives were cut short were accompanied by the ominous undercurrent that this tragedy has not yet ended.

In the days, weeks and months following the attacks, approximately 40,000 people found themselves involved in rescue, clean-up, and investigation efforts. These brave American heroes were assured by the Environmental Protection Agency that there was no health hazard detected at ground zero. However, five years after the attacks, it is becoming clear that these responders may have been deceived.

Medical professionals are discovering a rise in respiratory disease in 9/11 responders, which may be linked to exposure to the toxic dust at ground zero. According to Anthony DePalma's report in the New York Times, "it is still too early . . . to say with certainty whether any long-term cancer threat came with exposure to the toxic cloud unleashed by the trade center collapse. But there are already clear signs that the dust, smoke and ash that responders breathed in have led to an increase in diseases that scar the lungs and reduce their capacity to take in and let out air."

What began as a general hacking and congestion known as the "World Trade Center cough" which immediately plagued many responders, has led to a set of serious diseases and disorders including pulmonary fibrosis and

scardoidosis. Unfortunately, many of these diseases take years to develop making it difficult to concretely link the cause to 9/11. To date, pulmonary fibrosis has claimed the lives of Firefighter Stephen Johnson, Police Officer James Godbee, Detective James Zadroga, and telephone worker Mark DeBiase. However, due to the nature of these diseases, we may only be seeing the tip of the iceberg. It is likely that many more individuals will develop the disease in the coming years.

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*"It is disturbing that these courageous individuals put their lives at risk to aid others in one of our nation's darkest hours and are now being overlooked,"*

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For some who have begun to exhibit symptoms, there is a greater foe than the disease itself. Many responders were employed by departments with unions, opening avenues to ensure that 9/11 related health issues are acknowledged and that appropriate pensions are received. However, many volunteer workers came from various organizations across the nation and may now be left without health coverage as symptoms begin to emerge and worsen.

Pulmonary fibrosis patient Vito Valenti worked near the WTC and offered his time to distribute water and supplies at ground zero. After being diagnosed with post-traumatic stress disorder requiring him to take many months of leave, he was struck by pulmonary fibrosis rendering him unable to work. According to the New York Daily News,

Valenti is one of many "who are barred from filing claims because they realize they are sick more than two years after 9/11, the time limit for starting a case. His only hope rests in legislation that would extend the filing period for 9/11 responders." However, because he declined to join the city retirement system before 9/11, it is unclear whether he is entitled to a disability pension provided to those who were disabled after responding to 9/11. While he awaits the verdict, his medical coverage has expired leaving him with no way to afford his medications or the supplemental oxygen necessary to keep him alive.

"It is disturbing that these courageous individuals put their lives at risk to aid others in one of our nation's darkest hours and are now being overlooked," says Foundation President Dr. Michael Rosenzweig. "We as a nation must focus our attention to helping and supporting them in their time of need as they did for us."

Due to the lack of awareness of pulmonary fibrosis, the Foundation would like to be proactive regarding the health situation that is arising in the aftermath of 9/11. It is our hope to launch a comprehensive campaign to reach out to those suffering from the "World Trade Center cough" and provide the support and information necessary for them to get the care they need and deserve. I am sure you have been touched by the plight of the volunteers and rescue workers, who now can't breathe and can't afford the daily oxygen needed to survive. We hope you will consider helping us to make a difference in lives of these brave American heroes.

*(Source: New York Times May 13, 2006 & New York Daily News August 10, 2006)*

### Do you have a story to tell?

**The Foundation knows that everyone's experience with pulmonary fibrosis is unique and, if shared, can be helpful to others dealing with the disease. If you or a loved one is battling pulmonary fibrosis, we hope you will consider sharing your story with the Foundation to serve as inspiration to others. For more information, please call Leanne at 312-587-9272.**

## Finnish Researchers Detect Possible Gene for Familial IPF

A recent study by researchers at the University of Helsinki Hospital in Finland has found the ELMOD2-gene to be a possible candidate gene for familial pulmonary fibrosis. In their previous studies, these researchers observed that the incidences of idiopathic pulmonary fibrosis (IPF) were unevenly distributed across Finland. They found the prevalence to be two times higher in eastern and southern Savo compared to the prevalence in Finland. After identifying multiplex families with IPF, researchers noticed that familial IPF patients were clustered within Savo and Carelia, the same areas with the high prevalence. This finding suggests that these individuals may share a common disease-causing allele introduced by a common ancestor. For the entire article, please visit [www.medicalnewstoday.com/printerfriendlynews.php?newsid=46486](http://www.medicalnewstoday.com/printerfriendlynews.php?newsid=46486).

## New Support Groups

The Pulmonary Fibrosis Foundation has launched two new online support groups to meet the needs of our supporters.

Realizing that pulmonary fibrosis affects not only the patient, the Foundation has created a caregivers support group, which can be accessed by visiting: <http://health.groups.yahoo.com/group/Breathe-SupportCaregivers>.

The Foundation has also launched a support group for those individuals who are mourning the loss of a loved one. To connect with others coping with grief, visit <http://health.groups.yahoo.com/group/Breathe-SupportGrief>.

Also, our online patient support group is still available and is as strong as ever. It is accessible by visiting <http://health.groups.yahoo.com/group/Breathe-Support>.

If you have questions or concerns regarding our online support groups or would like information about face-to-face support groups in your area, please contact the Foundation at (312) 587-9272.

## Seasonal Health Concerns for Patients

As the cold and flu season approaches, the Foundation would like to remind patients of some small measures they can take to stay healthy.

- Get a flu shot
- Make sure your pneumonia shot is up-to-date
- Avoid overly crowded environments where there may be an abundance of germs
- Ask friends and relatives to call instead of visit if they suspect they may be ill
- Wash hands frequently
- See a doctor immediately if you begin to experience any unusual symptoms



**Yes!** I want to support the work of the Pulmonary Fibrosis Foundation by making a contribution.

Donation Amount:  \$5,000  \$1,000  \$500  \$100  \$50  Other \_\_\_\_\_

Restrict my donation for Research  Use my gift where the need is greatest

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

Please send your check to:  
Pulmonary Fibrosis Foundation,  
1332 N. Halsted Street, Suite 201,  
Chicago, IL 60622

If you would like to charge your Contribution:  Visa  MasterCard  Discover  American Express

Account Number \_\_\_\_\_ Expiration Date \_\_\_\_\_

Credit Card Contributions may also be made by Phone: (312) 587-9272 or Fax (312) 587-9273

## PF Patients Can Now Take Flight

Air travel has become easier for pulmonary fibrosis patients thanks to the Federal Aviation Association's decision to allow use of Portable Oxygen Concentrators (POC) onboard commercial airlines. The rule, classified as a Special Federal Aviation Regulation (SFAR), became effective on August 11th, 2005, but until recently, most airlines have still prohibited passengers from bringing their own POC onboard. Passengers who require supplemental oxygen were required to use devices provided by the airline at a considerable cost. The development of the Inogen One and the AirSep Lifestyle has caused many airlines to rethink their oxygen device policies. Currently, Inogen One and the Lifestyle are the only POCs approved by most major airlines on a case by case basis.

Unlike conventional oxygen tanks which are heavy and store oxygen in a pressurized cylinder, Portable Oxygen Concentrators filter nitrogen from existing air to deliver a therapeutic concentration of oxygen to the user.

Both the Inogen One and the Lifestyle are small in size, very lightweight (weighing approximately 10 pounds) and fit easily underneath airline passenger seats. Both are powered by batteries or may be plugged into a power outlet, and both have a setting range from 1-5 liter per minute (LPM). The Lifestyle has an optional battery pack which can hold up to four batteries each lasting about 45 minutes on 2LPM. However, the Inogen One batteries last about three hours on 2LPM. Both devices have optional carts available to carry the unit and extra batteries.

Airlines that have approved the use of these devices are listed to the left.

Even if your airline allows the use of the Inogen One or Lifestyle devices, it is important to contact the airline to determine any documentation or arrangements that may be required. For more information on Inogen One, visit [www.inogen.net](http://www.inogen.net) or call 1-800-877-4-INOGEN. Additional information on Lifestyle can be found at [www.airsep.com](http://www.airsep.com) or by calling (716) 691-0202.

### The following airlines allow the use of Lifestyle on their aircrafts:

ATA Airlines	Southwest Airlines
Alaska Airlines	Sun Country
America West	US Airways
American Airlines	ANA Airline
Colgan Air	Air France
Continental	British Airways
Delta Airlines	Cathay Pacific
Frontier Airlines	JAL
Hawaiian Airlines	Lufthansa
Midwest Airlines	Qantas
North American Airlines	
Piedmont Airlines	

### The following airlines allow the use of Inogen One on their aircrafts:

Air France	Lufthansa
Alaskan Airlines	Midwest Airlines
Allegiant Air	Northwest Airlines
America West	Qantas
American Airlines	SAS Airlines
ATA Airlines	Southwest
Delta	Sun Country
Frontier	USA 3000
Hawaiian Airlines	

## Foundation Welcomes Beren to Board of Directors



The Pulmonary Fibrosis Foundation welcomes Daniel Beren of Harrisburg, PA as the newest member to its Board of Directors. Daniel heads the State Government Relations activities of Buchanan Ingersoll and has experience both as a legislator and as a lobbyist.

As a legislator, Daniel served for 10 years as a distinguished member of Pennsylvania's General Assembly,

gaining positions of seniority on a variety of important committees, including Transportation, Judiciary, Mines and Minerals, State Government, Elections and Apportionments, Rules and Urban Affairs. Daniel has most recently been honored by being selected to be the first keynote speaker at a ceremony honoring all present and past members of the General Assembly.

As a lobbyist since 1977, Daniel has successfully secured passage of many pieces of major legislation. He has accomplished major legislative victories in the areas of taxation, transportation, banking, insurance, thoroughbred racing, liquor code, corporate management, the environment, funding for health care, higher education and

stadiums.

Daniel lost his wife of 49 years, Joan Cranmer Beren, to idiopathic pulmonary fibrosis in February 2006. Joan's twin sister, Jane, also passed away from pulmonary fibrosis in 2000. A memorial fund has been established in Joan's memory with 100% of the donations being allocated to research to find a cure for pulmonary fibrosis.

Since joining the Foundation's Board, Daniel has already been instrumental in getting the appropriations committee to call for more funding of pulmonary fibrosis research.

## Turning Grief into Gumption

Pulmonary fibrosis has torn through many families leaving in its wake fear, sadness, and anger. However, there rises from the despair, a few great individuals who have found ways to turn their grief into gumption. They have learned to channel their desire to honor their loved ones and find a cure for this disease into active ways to raise awareness.

Tom Hewitt is one such individual, who has gone above and beyond the norm to make a difference in our quest for a cure. Tom and his father, Paul, started Image Crazy Designs, a screen printing and promotional items business, in 2004.

"My father, although he had a full time career as an engineer at Nortel in Durham, NC for over 30 years, helped me every step of the way in building this screenprinting and promotional items business," says Tom. "During this time our father and son bond was rekindled and strengthened, and we also became the very best of friends."

Not long after the founding of Image Crazy Designs, Paul began having difficulty breathing. His doctors feared it was caused by idiopathic pulmonary fibrosis. Tom remembers that the two discussed the disease as if there was a pill he could take to fix it, and went about their day as usual. A short time later, Paul underwent a biopsy. The doctors confirmed their suspicion, and diagnosed Paul

with pulmonary fibrosis at the age of 52.

The Hewitt family struggled to comprehend the gravity of the diagnosis, while continuing to build their business. Despite his full time job, Paul put in a lot of his free time helping to get Image Crazy off the ground. It wasn't until he

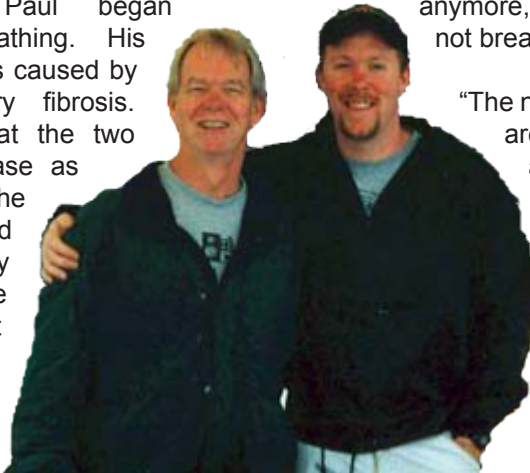
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*"The next few weeks are still a blur, a series of ups and downs as we learned of my Dad's disease first hand. . ."*

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was forced to use a portable oxygen tank that his family began to realize this was more serious than any of them had originally thought.

The day that permanently changed the lives of the Hewitt family came in late January 2005. Paul was taken to Duke University Hospital in Durham. He could not even walk up the stairs anymore, and he could not breathe.



"The next few weeks are still a blur, a series of ups and downs as we learned of my Dad's disease first hand," says Tom. "I held my Dad's hand as he

took his last breath on February 11th, 2005 at 52 years old, a mere 3 months after he was diagnosed."

"I could describe my father, Paul Hewitt, in numerous ways. However, the ones that come to mind most often are a great Dad, a trusted mentor and, most importantly to me, one of my very best friends. I miss him every day of my life."

Following Paul's passing, Tom's brother joined in running Image Crazy Designs. A short time later, inspired by the pink breast cancer movement, the brothers decided to use their talents and abilities to raise awareness of the disease that robbed their father of his life.

The website [www.helpfightpf.com](http://www.helpfightpf.com) launched in Fall 2005 and offers Pulmonary Fibrosis Foundation T-shirts and mugs as well as red and blue "Breathe" bracelets with many more items scheduled to be added this fall.

"Our number one goal at helpfightpf.com is raising awareness by providing custom imprinted items with a message," says Tom. "I feel it is important to raise awareness about this terminal disease, which most people have never heard of. The more of a household name we can make it, I feel the easier it will be to get funding and support to find a cure"

In addition to selling Foundation merchandise, Image Crazy Designs has aided many of our dedicated volunteers in the creation of customized items for their fundraising events. If you are hosting an event and would like help creating promotional items, please contact Tom Hewitt at 910-980-1604.

## Merchandise with a Message



**Help Fight Pulmonary Fibrosis**  
It affects us all



[www.helpfightpf.com](http://www.helpfightpf.com)

## 50/50 Campaign Update

The 50 Events in 50 States Fundraising Campaign aims to spread awareness of pulmonary fibrosis and raise funds for research across the nation. These fundraising events are vital to our success. The Foundation would like to thank the following individuals for offering their time to host an event. More information can be found at [www.pulmonaryfibrosis.org/events.htm](http://www.pulmonaryfibrosis.org/events.htm).

### By press time, seventeen events have been completed:

#### Arizona

- The Donna C. Price memorial archery "Shoot for a Cure" at Granite Mountain Archery range in Prescott.

#### California

- Cathedral Oaks Athletic Club held a 1-hour swim fundraiser in honor of Marcia Rowlands
- 5<sup>th</sup> annual golf tournament in memory of Bernice Dunlop

#### Florida

- Maria Morgan has completed a letter writing campaign as well as hosted a fundraiser at two Florida Panthers hockey games in memory of her mother, Olga Lopez

#### Maryland

- Golf tournament hosted by Barb Hunter in honor of her good friend, Greg Marvel

#### Massachusetts

- Doug Bernard and family hosted a fundraiser at the Quincy Knights of Columbus in memory of his mother, Judith A. Bernard.

#### Michigan

- 2<sup>nd</sup> Annual "Paddle out Pulmonary Fibrosis" canoe marathon in memory of the Dery and Willacker families

#### Montana

- The Knievel family sold bracelets at Evel Knievel Days to benefit the Foundation (*see full story on page 2*)

#### New Jersey

- Bowling party hosted by Stephanie Shupack in memory of her father, Ronald Schuster.

#### New York

- 2<sup>nd</sup> annual cocktail party hosted by Shane Parouse and friends in memory of Jim Stephens
- 3<sup>rd</sup> annual golf tournament hosted by Joe Maltese, Jr. to honor his father, Joe Maltese Sr.
- Rachel Wilgoren embarked on a cross-country fundraising road trip in memory of her mother, Toby Neipris Wilgoren. (*see full story on page 8*)

#### Ohio

- 4<sup>th</sup> annual Mother's Day Gift Basket Raffle and bake sale hosted by Vicki L. Mountain in memory of Lawrence O. Bray.

#### Pennsylvania

- Benefit bike run and picnic hosted by Rob Fiorillo and family in memory of Barbara A. Fiorillo.

#### Rhode Island

- Bike run and walk hosted by Ken Galyas in honor of Evel Knievel and to help raise awareness of pulmonary fibrosis.

#### Virginia

- Fundraiser at the Langley Speedway in memory of former Vice President and GM, King Hodges.

#### Canada

- Tania Farrell hosted a Pub Event in memory of her father, Peter Joseph Farrell.

### The following events scheduled for later this year:

#### Illinois

- Dinner and Dancing at the Morton Grove Moose Lodge to raise awareness and money in memory of Darlene Hohman.
- Susan Heizer is conducting a letter writing campaign in honor of her sister, Diana Larson.

#### Massachusetts

- 2<sup>nd</sup> annual golf tournament hosted by the O'Leary and Leverone families to help "drive out" pulmonary fibrosis.
- 2<sup>nd</sup> annual golf tournament in memory of Dick Hallion hosted by Rob Hallion and family.

#### Pennsylvania

- 2<sup>nd</sup> annual Wescoe Walk hosted by Jennifer Wescoe-Schaninger and family and friends in memory of her father, Ron Wescoe.

### The following events are currently scheduled for 2007:

#### California

- A wine tasting will be held on May 17, 2007 in memory of Wilbur Smith.

#### New Jersey

- Sandra Lewis will be hosting "A breath of fresh air" cocktail party in honor of her mother Judy Bean on May 11, 2007

**Our volunteers have raised \$82,205 for research in 2006!!**

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If you would like to be removed from the mailing list please fill out this form and mail it to:

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1332 N. Halsted, Suite 201  
Chicago, IL 60622-2691

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_

State: \_\_\_\_\_ Zip: \_\_\_\_\_

## A Roadtrip to Remember

Following the death of her mother, Toby, on Mothers' Day of this year, Rachel Wilgoren and her brother, Peter, began searching for creative ways to celebrate her memory and raise funds to find a cure for the disease that stole her life.

The answer became clear when the two siblings considered their parents' dream of touring the country as newlyweds. The dream was put on hold when Toby discovered she was pregnant with Rachel and was never fulfilled due to the death of their father when the children were teenagers.

On July 1, 2006, Rachel, accompanied by friend Rose-Ellen David, left her New York City home and began her 11,500 mile cross country quest to gain perspective on her loss and reach her \$10,000 fundraising goal for the Pulmonary Fibrosis Foundation.

During the trip, Rachel collected rocks, stones, and gems from the various

places she visited to decorate her mother's grave, a Jewish tradition in some communities. Among them are beautiful rainbow treated stones and



*Rachel Wilgoren placing stones at her mother's grave. (Photo by John Harvey of The Sharon Advocate.)*

geodes from Vancouver, petrified wood from the Grand Canyon, a gorgeous calcite piece and a green quartz piece from Sedona, and smooth rocks and a

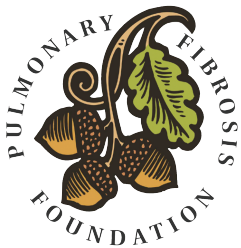
marble from Marj.

"The point, though, is that Mom was with me throughout the trip, and a piece of each of these places will be with her permanently," says Rachel.

The two-month journey ended on August 28 with a visit to Rachel's 95-year-old grandmother in the same nursing home where Toby spent her last months, and, finally, to the family grave, where Rachel began to plan a mosaic border of the stones she'd collected.

To date, Team Toby has raised \$3,455 of their \$10,000 goal.

To read more about Rachel's moving cross-country voyage, visit her travel blog at [www.teamtoby.net](http://www.teamtoby.net).



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