

# Westie Owners Launch GoFundMe Page, Raise Funds For Innovative IPF Study

By Teresa Barnes

**P**J Kessler is a dog owner on a mission to solve a deadly lung problem in West Highland White Terriers. Not only did she create a Facebook page for owners whose dogs suffer from pulmonary fibrosis (PF) also called Westie Lung Disease (WLD), she created a GoFundMe page [<https://www.gofundme.com/wfa-pulmonary-fibrosis-drug-study>] to help researchers study a promising therapy to treat it.



“Tyler”

Kessler understands IPF far too well. She lost a Westie 10 years ago from the deadly lung disease characterized by progressive and irreversible scarring. Dogs develop an uncontrolled cough and shortness of breath that makes walking and even eating difficult and over time robs them of their quality of life.

When her Westie, Tyler, was diagnosed in 2014, Kessler decided to take action against the devastating illness. Tyler was treated at the University of Minnesota by Lindsay Merkel, DVM and was responding well to a class IV laser therapy that was being used by Merkel to help improve Tyler’s quality of life. She knew, however, the laser wasn’t going to save him.

Kessler heard about a project being proposed to study pulmonary fibrosis and reached out to Westie Foundation of America (WFA) to confirm it. She learned the study was being coordinated by the WFA and WFA was matching a top human pulmonary fibrosis research center and a top canine research center – Yale University in humans and Tufts University in canines. The study was looking at a thyroid hormone mimetic as a potential therapy. The drug they were considering was successful in phase I clinical studies in humans and preliminary research done at Yale University pointed to the possibility that the drug could be repurposed for Pulmonary Fibrosis.

Wasting no time, Kessler shared with the WFA her wish to create a GoFundMe account to help raise the \$30,000 needed to do the study. The WFA provided details about the study and Kessler launched the page and began sharing it with her Facebook page followers.

The fund raised \$500 within the first few hours and to date, has raised close to \$11,000.

Colleen Turgeon was one of the fund’s first donors. Turgeon lost her Westie, Daisy, in 2016 to WLD and her heart still ached. “Because I watched my sweet Daisy suffer with this disease, I really want there to be a cure or at least a treatment that makes

a difference. She went undiagnosed for so long – nobody knew what she had until it was too late,” said Turgeon. “My hope for this study is that we get closer to a cure – and at least a viable option for treatment.”

Claudia Gurlock, who has a background in medical research and drug and device development, also supported the GoFundMe effort after experiencing the loss of her Westie in 2017. She joined Kessler’s Facebook group soon after the diagnosis and that is where she learned about the GoFundMe effort.

“It was quite easy to donate to the GoFundMe page. I wanted to participate and raise awareness for this horrible disease that affects our Westies,” Gurlock said. “I hope that the study will be able to provide data showing that the use of this thyroid medication on dogs diagnosed with WLD is successful and may stop the progression of the disease, slow the progression, or cure it. Ultimately, it would be wonderful if it could be a precursor to human drug studies for IPF.”

Some Westie owners are reaching out to friends and family to help raise the funds needed for the study and others are asking their co-workers. Jesse Torres felt so strongly about the funding campaign, he placed a cup decorated with a photo and story of his dog, Cody, who suffers from WLD in his workplace. Torres office staff have donated \$100 and counting.

Kessler has re-launched a tee-shirt sale to add to her GoFundMe efforts to fund the study. The Bonfire WLD Warrior Club shirt drive offers Westie adorned tee-shirts for sale.

With any luck, Kessler plans to complete the funding needs for the study by raising the additional \$19,000. “We need a cure for this disease that takes so many Westies lives every year. I am committed to helping find a cure,” Kessler said. “It absolutely breaks my heart that so many Westies are dying daily from this horrible disease.”

WFA’s President, Bebe Pinter says Kessler’s effort has been hugely successful regardless of the amount of money it raises. “We are happy to see this effort, led by PJ and funded by Westie owners. It demonstrates what we always knew was true: There is no better breed than the West Highland White Terrier and the people who own and love them are exceptional in their commitment to the health of their dogs. They passionately go after opportunities to help their dogs and our Westie breed.”

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(GoFundMe Page continued from page 10)

To join the closed Facebook Westie IPF/Westie Lung Disease group, visit [www.westielungdisease.net](http://www.westielungdisease.net) and ask to join the group.



“Dr. Merkel and Tyler”



“Tyler”

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**A** year ago, a study was published on a promising new drug. The headline read: “Thyroid hormone therapy heals lung fibrosis in animal study.” It was published by a renowned scientist at Yale, Naftali Kaminski, MD, in *Nature Medicine* and entitled: **Thyroid hormone inhibits lung fibrosis in mice by improving epithelial mitochondrial function.** To read the study, visit: <https://www.nature.com/articles/nm.4447>

The Yale team led by Kaminski took a look at all of the genes expressed in the lungs to see which genes were increased in them. They found that one gene that was increased also has a role in activating the thyroid hormone.

The curious researchers decided to examine the link between the hormone and IPF. When the team used an aerosol version of the hormone, it enhanced the resolution of fibrosis and reduced their fibrosis compared to healthy controls. The researchers also happened upon something unexpected: It has recently been suggested that in fibrosis, mitochondria, or small organelles that regulate cell metabolism – don’t function properly.

The team found the use of the thyroid hormone returned mitochondrial function to normal in the cells that line the air sacs in the lung. The team believes that this process of normalizing metabolism protects the cells from damage and allows fibrosis to resolve.

Kaminski said they needed to do further study to see if there was a role for this thyroid hormone in the treatment of Pulmonary Fibrosis (PF). The drug wasn’t new, but it was a new concept in the treatment of fibrosis. The drug, thyroid hormone mimetic, Sobetirome, is considered to be safe in humans and may represent a promising and innovative idea for a study of a deadly lung disease that claims the lives of many West Highland White Terriers around the world.

### Enter the WFA.

The WFA’s Communications Vice President and Board of Directors member, Teresa Barnes, knew Kaminski and reached out to him after reading about the research. She offered for the WFA to connect Yale with canine research experts at Tufts University to look at the thyroid hormone in naturally occurring IPF in Westie dogs. Kaminski accepted and within weeks, the collaboration was underway with the canine study being led by Elizabeth Rozanski, DVM, and the protocol was designed. All it needed to begin recruitment of dog patients was funding.

It didn’t take long for Westie advocate, PJ Kessler, to mobilize a group of dog owners to come to the aid of researchers by launching a GoFundMe page after she heard about the study. To date, the fund has raised a third of the money that will be required to launch the study. To donate to the fund, go to [<https://www.gofundme.com/wfa-pulmonary-fibrosis-drug-study>]. *Funds raised will benefit the WFA and go towards a pulmonary fibrosis canine study.*

(GoFundMe Page continued from page 11)

**The Westie Foundation of America (WFA) serves as a catalyst for life improvement and progress in Westie health and veterinary care. We need your help** to support a new study that has the ability to change the way Westies suffering from Pulmonary Fibrosis (PF)/Westie Lung Disease are treated and has the potential to greatly improve our dogs' lives. And It might even help people or cats with this condition!

We would like to get this study underway soon and need to raise \$30,000 to make it happen.

**What?** Pulmonary Fibrosis Study looking at new discovery of importance of thyroid hormone in treatment (link to study in Nature on the discovery: <https://www.nature.com/articles/nm.4447>)

**Who?** The WFA introduced two renowned research centers to look at this discovery and its potential efficacy in Westies with PF. Yale made the original discovery and Tufts has significant interest in Westies and PF. It is a match made in Westie Heaven.

**Why?** Pulmonary Fibrosis poses a significant burden on the quality of life of Westies that are affected and is a major cause of death in the breed. There are no therapies approved for treatment of PF in canines.

**When?** As soon as possible, the WFA would like to get financial support for this study to get it underway.

**Where?** The study will be housed at Tufts University and the University of Minnesota and dogs will be recruited for the study in the local area (unless owners from outside areas meet the logistical requirements of the study). Tufts researchers are already working with researchers at Yale to set up the study protocol and logistics – the only thing they need to get started is the funding to do the study.

### **Background on WFA's work in Pulmonary Fibrosis and with Canine/Human Researchers:**

The WFA works with the best scientists in the world on Westie health. We have a track record of coordinating and convening the world's greatest minds in veterinary and human medicine to tackle the most burdensome diseases in our breed. In 2014, we convened the first-of-its-kind *Fibrosis Across Species* three-day conference bringing together renowned scientists and clinicians from human and veterinary medicine. The resulting partnerships and strategies continue to pay dividends on our and our partners' investment – and because of donations by Westie owners like you. As a result of the information exchanged and shared at the meeting, the National Institutes of Health identified "fibrosis across species" as a priority in human Idiopathic Pulmonary Fibrosis research efforts. In 2007, we convened the first meeting of human and canine researchers looking at naturally-occurring pulmonary fibrosis (PF) in the Westie and explored tandem efforts to attack the disease. The WFA will continue to cover new ground

and pioneer strategies and tactics to solve the most confounding issues that affect the West Highland White Terrier.

### **WFA Vision for PF Research to Improve the Lives of Westies:**

Our vision is to expand our efforts to become a catalyst in Westie research efforts by proactively establishing research partnerships with universities, independent research centers and experts in industry including companies in the pharmaceutical, nutraceutical and medical device industries. We envision matching researchers with potential partners and resources to provide successful and sustainable Westie-related research programs.

### **A Partnership for Healthier and Happier Westie Dogs and Owners**

Together, we can build an all-new program that will advance research to improve the health and lives of Westies. We can make Westie ownership even more satisfying and rewarding. We can challenge the current research paradigm in Westie health and accelerate progress into finding treatments and cures for our dogs and hopefully humans. We can ensure that our leaders move us quickly in the direction of success and we fully capitalize on our research efforts and partnerships to drive innovation.

### **Okay, you've made a donation – Thank you! How ELSE can you help Westies?**

In addition to helping fund this study, we are also planning to have Westie families help determine the normal value for the 6-minute walk test in Westies! While we know this distance (which is a measurement that provides important information about progression of disease) in people and dogs, we don't know for sure about Westies, in particular. It is EASY and you can do it at home! We need both normal Westies, and Westies that been found to have pulmonary fibrosis.

#### **What you need:**

- 1) A Westie
- 2) An area to walk that is not filled with distractions, like a parking lot.
- 3) A smart phone that measures distance. You can also use an official 6 MWT app on your phone. 6MWDAPP.
- 4) Please participate, and then enter data here! <https://www.surveymonkey.com/r/SJSZGWK>

### **About The Westie Foundation of America**

*The mission of the Westie Foundation of America, Inc. is a 501 C (3) organization established to provide financial aid and other support for medical research in order to benefit the health and quality of life of West Highland White Terriers; and, to further develop and communicate information regarding the health, care, breeding and quality of life of Westies to Westie owners, Westie breeders and veterinarians. For more information visit [www.westiefoundation.org](http://www.westiefoundation.org).*