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## Thank You for Championing Parkinson's Research!

*Dear Participant,*

*Thank you for your dedication to Fox Insight. With over 20,000 participants, you are part of the largest Parkinson's disease (PD) research study in the world! Every time you log in to Fox Insight and fill out surveys, you are providing doctors, researchers, and drug developers with information to better understand Parkinson's from the true PD experts—patients and their families.*

*This is the first issues of the Fox Insight Newsletter. We will circulate two issues each year to keep you informed about study findings, updates, and new opportunities for participation.*

*Please let us know if there is a topic you would like featured in an upcoming issue. You can reach us at [info@foxinsight.org](mailto:info@foxinsight.org).*

*Your participation in Fox Insight is making the patient voice heard in research. Keep up the good work and log-in to your Fox Insight profile to complete your current study visit and check for new research opportunities.*

*Thanks for all you do,*

*The Fox Insight Study Team ■*

### About Fox Insight

Fox Insight is an online study to help researchers better understand what it's like to live with Parkinson's. Open to people with and without PD, Fox Insight captures important information through online surveys that volunteers can complete anytime, anywhere. By studying patient perspective information over time through Fox Insight, scientists can gain critical insights into how the disease changes over time, differs from person to person and effects quality of life.

Fox Insight is sponsored by The Michael J. Fox Foundation for Parkinson's Research. To learn more or volunteer to participate in the study, visit [www.foxinsight.org](http://www.foxinsight.org).

## Hot Topics in Research: Genetics and Parkinson's – What's the Connection?

Advances in genetics have led to many key discoveries in PD. Thanks to the participation of study volunteers (just like you), researchers can analyze data to uncover new links between genes and Parkinson's.

Just 20 years ago, most scientists believed that Parkinson's was caused by unknown environmental factors. Then researchers collected and analyzed DNA samples from a large family with a history of PD. From these samples, scientists found the first gene linked to PD. It was a game-changing discovery that led to a new understanding: genetics can influence the development of PD. This detective work in genetics is critical to advancing PD understanding. It's pushing research in ways that could change medicines and treatments for the disease. Today, scientists are tracking the ways genetic factors influence Parkinson's. While there's much that has been uncovered, there is still much to learn.

As a participant in Fox Insight, you may be eligible to contribute to genetic research through a collaboration with 23andMe. If you have been diagnosed with PD, live in the United States, and have completed one study visit in Fox Insight, you can add your genetic data. Sign in to Fox Insight to check your eligibility or email us at [info@foxinsight.org](mailto:info@foxinsight.org) to learn more. ■



# Participant Profile: The DiBiaso Family Shares Their Story

*When Peter DiBiaso was diagnosed with Parkinson's PD in 2015, he and his wife Vicky asked "What's next?" Participating in Fox Insight has been just one of the next steps the couple has taken on together.*

Peter and Vicky DiBiaso have spent their professional careers in pharmaceutical research and development. They have both worked for more than 20 years supporting clinical trials to develop medicines for many different diseases. Part of their professional and volunteer experiences have also been to help educate and connect patients to research opportunities as part of a health care options. So when Peter was diagnosed with Parkinson's disease three years ago, becoming active volunteers in the Parkinson's community was a 'no-brainer.' "I am aware of the time it takes to advance research," Vicky said, "and the only way to reduce that time is to have more people involved in research."



The DiBiasos began their personal journey in Parkinson's research with Fox Trial Finder, the Fox Foundation's clinical trial matching tool. They learned about a variety of studies including Fox Insight. "Fox Insight was a unique way to be part of the journey to a cure that is low impact and a low time commitment" Peter said. "It is a good benchmarking tool for me as I periodically fill out my assessments. I can see if certain things are changing or staying stable." Also contributing genetic data to Fox Insight through 23andMe, Peter was excited to "take full advantage of every option to answer questions for research *and* get information back to further my own diagnosis."

## Fox Insight by the Numbers

*(As of July 23, 2018)*

- 22,100+** Participants enrolled
- 4,200+** Participants agreeing to add their 23andMe genetic data
- 1074** Participants consented to complementary genetic counseling
- 9** Scientific presentations featuring Fox Insight Data in 2018!

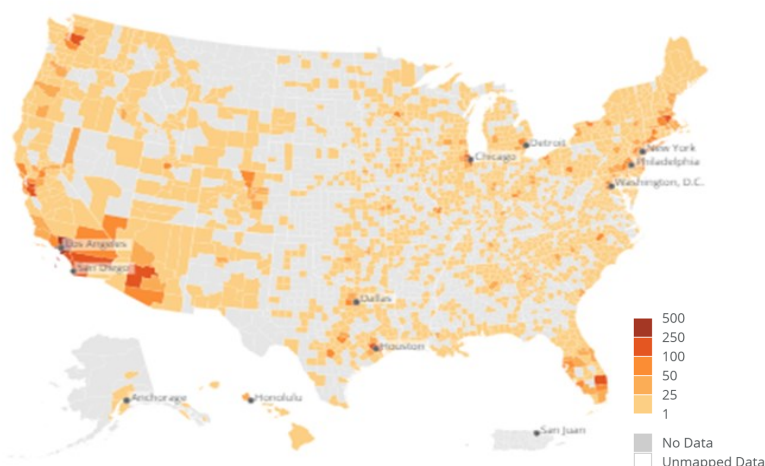
Vicky also volunteers in Fox Insight, contributing data as someone without PD and encouraging others to join the study. "Aside from being Peter's wife in a marriage, participating in research is something I can tangibly do to help. And, it really does take a village to find the cure," Vicky said. "Since the time Peter was diagnosed, we've had an outpouring of friends ask if there is anything they can do. What we've encouraged friends and family to consider is participating in research so we can better understand what causes Parkinson's. The more data we collect, and at a faster pace, is what will enable researchers to speed a cure!"

Peter and Vicky have built strong connections in the Parkinson's community. Not only do they participate in research, but they also are involved in Team Fox athletic events! Both ran the New York City Marathon in 2016 and 2017, and this year will reach new heights as they climb Mount Kilimanjaro with Team Fox. ■

**Help us light up the map!** As seen in the map, Fox Insight participants span all fifty states — but we are looking for even more volunteers!

**Share Fox Insight with your community.** To get flyers, postcards and swag to share at your support group, doctor's office, 5K, marathon, or any other Parkinson's event, email: [info@foxinsight.org](mailto:info@foxinsight.org). ■

**DID YOU KNOW?** While the majority of participants live in the US, did you know Fox Insight is a global study? There are nearly 5,000 subjects living outside of the US across 108 countries!



## Researcher Spotlight: Ira Shoulson, MD

*Dr. Ira Shoulson is a professor of neurology, pharmacology and human science and director of the Program for Regulatory Science and Medicine at Georgetown University Medical Center. Dr. Shoulson developed the “What’s Bothering You About PD” questionnaire administered through Fox Insight. We sat down with Dr. Shoulson to understand why he thinks this study is groundbreaking.*



### Why is Fox Insight important and how is it filling a gap in the current research landscape?

Fox Insight is giving patients a voice, elevating their experiences to better understand what it means to live with Parkinson's disease (PD). After all, patients are the true PD experts, and they should have a platform to share their story.

Fox Insight is so powerful because there are so many participants. Among Parkinson's researchers and companies developing new treatments, there is high interest in looking at volunteer responses in Fox Insight to better understand what is important to patients.

### You developed a questionnaire that is part of Fox Insight that allows patients to share what bothers them most about Parkinson's disease. Can you tell us about it?

This survey captures what patients say in their own words without being filtered by a clinician. Over 10,000 Fox Insight participants with PD have answered the open-ended questionnaire. That's probably 10,000 more people than researchers have ever heard from—people who are sharing what bothers them the most about PD and how it impacts their lives.

### Are there any initial findings you can share?

After reviewing responses to date, we see that what bothers people most varies from patient to patient, but when you have tens of thousands of people sharing their opinion you start to see some very clear trends. This question has never been asked in a systematic fashion, and especially not at such a large scale.

We've already given two scientific presentations using the first response from 5,000 patients. Through this process we've learned several things. In addition to tremor, rigidity, bradykinesia (slowness), and tendency to fall, there are a host of “non-motor” problems that are bothersome to people living with Parkinson's, which are often of greater concern, such as sleep changes, constipation, fatigue, ability to think, pain and changes in mood. These are things that may not come to the forefront when thinking about PD, but through this survey the research community is learning they are important, frequent, and can affect daily function even more so than motor problems. Perhaps this is not surprising to patients, but it's a new insight for scientists, and the Parkinson's research community is excited about the results. I want to thank every person who has participated in Fox Insight. You make this research possible. By continuing to participate, Fox Insight volunteers help researchers have valuable data that bring us closer to better treatments. ■

## Meet the Fox Insight Team!

We'll be at Fox Foundation events around the United States meeting study volunteers and sharing news about Fox Insight. Find out if we'll be coming to a city near you:

Cleveland, OH (August 11): Clinical Research Fair

Hockessin, DE (September 15):

[Pancakes for Parkinson's](#)

Boston, MA (October 21): [Fox Trot 5K Run/Walk for Parkinson's Research](#)

## Call For Volunteers: Join the Fox Insight Beta Tester Team!

Help improve the Fox Insight participant experience by joining the Fox Insight Beta Tester Team! We will seek your feedback on new platform features and study messaging. The time commitment will be approximately 2 hours each month. The group will be chaired by study participant Will McIntyre, who is eager to get things started:

*"When I was diagnosed with PD, I knew I had to do more than just 'have' the disease," said Will. "But I wasn't a doctor. I wasn't a scientist. Then, I met the inspiring team at Fox Insight and became involved in the study! As Beta Testers, we will provide the patient perspective on new questionnaires and overall study design. Your time commitment will only be about 2 hours monthly but to Fox Insight, it will be invaluable!"*

Sign up [here](#) to learn more about the Beta Testing Program!

## Back-page recipe: Blueberry Scones!

You share so much by participating in Fox Insight—our team wants to share something back with you. This issue, Dr. Katie Kopil from The Michael J. Fox Foundation is delighted to share her favorite blueberry scone recipe (at the peak of blueberry season in her home state, NJ)!

8 tbsp. (1 stick) unsalted butter, frozen whole  
 1½ cups (7½ oz) fresh blueberries  
 ½ cup whole milk  
 ½ cup sour cream  
 2 cups (10 oz) all-purpose flour, plus more for dusting the work surface  
 ½ cup sugar, plus extra for sprinkling  
 2 tsp baking powder  
 ¼ tsp baking soda  
 ½ tsp salt  
 1 tsp finely grated lemon zest  
 2 tbsp unsalted butter, melted

(serves 8)



Source: *Cook's Illustrated, Spring 2009*, via [Annie's Eats](#)

Preheat oven to 425° F. Grate the frozen butter using a large box grater. Place the blueberries in the freezer until needed. Whisk together the milk and sour cream in a medium bowl; refrigerate until needed. Combine the flour, ½ cup sugar, baking powder, baking soda, salt and lemon zest in a medium mixing bowl. Whisk to combine. Add the grated butter to the flour mixture and toss with fingers until thoroughly coated.

Add the milk mixture to the dry ingredients and fold with a spatula just until combined. Transfer the dough to a floured work surface. Dust the top of the dough with flour, and knead with well-floured hands, 6-8 times, just until the dough holds together in a ragged ball. Add small amounts of flour as needed to prevent sticking.

Roll the dough into a 12-inch square. Sprinkle blueberries evenly across the dough, and gently press down to slightly embed. Roll the dough to form a tight log. Lay the log seam-side down and press into a 12 x 14-inch rectangle. Using a sharp, floured knife, cut into 4 equal rectangles. Cut each rectangle diagonally to form 2 triangles. Transfer to a baking sheet, brush the tops with melted butter and sprinkle lightly with sugar. Bake until golden brown (18-25 min).

Do you have a recipe you would like featured in a future issue? Share it with [info@foxinsight.org](mailto:info@foxinsight.org)!