

# The VOICE of FTD

SUMMER 2021

## Featured Researcher:

*Dr. Karen Nuytemans, Research Assistant Professor, University of Miami*

Piece by piece, science is putting together the puzzle called frontotemporal degeneration (FTD) whose complete picture is still unknown. Karen Nuytemans, Ph.D., research assistant professor, Human Genomics, at the [University of Miami](#) (UM), sees genetics as one of the key pieces to that puzzle.

“I always say it’s the most cliché thing, but it’s a puzzle, and we’re trying to figure out what is happening in all of these diseases. Genetics seems to be a pretty significant part for all of them,” said Dr. Nuytemans, whose research focuses on the genetics of neurodegenerative brain disorders. “If we can understand what genes are affected by mutations, we can actually begin to understand what the biology is.”

Dr. Nuytemans said she was fortunate that near the start of her career, **next-generation sequencing** (NGS) was a new technology. DNA sequencing began in the 1970s, followed by NGS in the early 2000s. NGS has revolutionized the biological sciences, allowing researchers to look at the whole genome or large parts of the genome in one experiment across many individuals. It is accelerating biological and medical research.

The timing enabled Dr. Nuytemans to learn the field from its beginning. She now has extensive experience working with 'big data' datasets, including genotyping and NGS data, to identify common and rare **genetic variants** contributing to disease.

“It was a steep learning curve, but it was a steep learning curve for everybody at the same time,” she said. “It was good for me as a trainee to dig a bit deeper and really understand what was going on. I got to learn it from the ground up and grow with the technology.”

### Research Interests

Dr. Nuytemans is specifically interested in FTD, dementia with Lewy bodies (DLB) and Parkinson’s disease (PD). She said that DLB is largely understudied genetically, in any population; while genetic research in FTD and PD, so far, has primarily focused on population groups of European ancestry.

“Everyone, regardless of race, ethnicity, or socioeconomic status, should have access to **personalized medicine**,” she said, which is why she is focusing on these disorders across diverse populations.

This month Dr. Nuytemans is wrapping up a two-year [National Institutes of Health](#) (NIH) study; and on

*Please note that [this glossary](#) is available to help you understand the scientific terms used in this article. Glossary terms are shown in bold the first time they appear.*

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July 1, 2021, she will begin a four-year [Department of Defense \(DOD\)](#) study. Both are directed at [Genetics of Frontotemporal Degeneration in Diverse Populations](#), to better understand the genetic factors contributing to FTD in Hispanic and other minorities.

While this FTD study is recruiting persons from across the United States, there is a high percentage of Hispanics who live in the Miami area for Dr. Nuytemans to directly reach out to and try to recruit. About 30 to 40 percent of the UM hospital patients are Hispanic, she noted. The percentage of Hispanics is even larger in the general population in certain areas within greater Miami.

“We do reach out to the general population and go to caregivers and patient groups and aging centers” to recruit locally for studies, she said. “We try to find those extra puzzle pieces that are missing for diverse populations in these disorders.”

## Background

Dr. Nuytemans was born and raised in Belgium where she attended school and earned a B.S. degree in chemistry, an M.S. degree in biochemistry, and her Ph.D. in biochemistry and biotechnology from the University of Antwerp. She enjoys the warm sun and water of the Atlantic Ocean in Miami compared to the cold North Sea, but misses the four seasons of her native land.

Eleven years ago she moved to Florida as a post-doctoral fellow at UM and through the years has advanced to her current position of research assistant professor. As a junior faculty member, she teaches genomics medicine and still does most of the lab work for her projects. Since she is not a medical doctor, Dr. Nuytemans does not see patients.

“I’ll do the genotyping for the FTD study, or do some cell work testing the effect of some of the identified genetic



variants for Parkinson’s disease projects or projects for Alzheimer’s disease,” she said. “For the enrollment part of the studies, Anisley, our study coordinator, does all of the leg work. She is invaluable to the project.”

The UM labs were closed for several months in the spring of 2020 due to the coronavirus pandemic, but Dr. Nuytemans said she was able to return in the summer to resume doing the lab work for the studies with which she is involved. She continues to ride the train from her house on the south side of the city to the [Leonard M. Miller School of Medicine](#).

The train “has been pretty safe during COVID-19, with mandatory masks, hand washing dispensers, and extra security to make sure everyone is wearing their masks,” she noted. “Even with corona, there were still too many people on the road for me to want to (drive) that every day.”

Back on campus, Dr. Nuytemans spends half of her time in the lab and half of her time either doing analysis or administrative tasks on her computer. Her bibliography includes more than 30 citations, which can be found on the [NIH National Library of Medicine, National Center for Biotechnology Information](#).

In addition to her daily responsibilities, Dr. Nuytemans also works with area high school seniors through a

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[summer internship program at the university.](#) Each year about a dozen youth are selected from more than 100 applicants. The students are from diverse backgrounds in terms of schools — public, private, and underserved — as well as culture — Hispanic, African American, Asian, and non-Hispanic whites.

“In the last few years I’ve had the chance to work with many Hispanic students. They love being able to work on a study that looks at genetics in Hispanic individuals. They feel included,” she said. “It’s good for them to see that there are studies that are trying, in a good way, to help their populations as well and trying to get them included. They’ve been so excited every year, and it excites me to see that.”

Outside of science, Dr. Nuytemans enjoys traveling and beer. However, the COVID-19 pandemic put her pastimes on hold.

“One of the other reasons I went into science is because I had examples when I was in college of Ph.D. students and faculty members who traveled to the scientific meetings in great places across the world,” she said.

Her enjoyment of beer comes from her upbringing in Belgium, a country that offers over 3,000 kinds of beers from more than 300 breweries. Dr. Nuytemans and her fiancé like to try beers from around the world.

“There are different styles of beers here in the U.S. versus in Belgium. We have a lot heavier triples and quads in Belgium,” she noted. “I, unfortunately, don’t like hoppy beers, which people in the U.S. generally drink.”

## Excitement in FTD

FTD was a focus of Dr. Nuytemans’ doctoral studies, and in the past two years she has returned to investigating

these disorders through grants. This is a very heady time for advancements in research within the FTD field, the scientist noted. Drug companies are taking information that scientists are finding and trying to design treatments that target the specific gene mutations.

“Genetics, in general, is exciting to me. I’m not into direct translational science, I’m primarily a basic scientist,” she said. “But it is exciting to see those papers and clinical trials coming out that use the information that my colleagues and I have figured out.”

Neurologists at the university let her know when they begin new clinical trials that are for patients with the various genetic mutations.

“I feel very encouraged by newer therapies that are coming out because they are more based on genomics and genetics, which is what I do. That is the direction the whole field is going — to personalized medicine,” she said.

It comes back to that puzzle.

“Every little piece of information helps us piece it together. And piece by piece by identifying these genes, we can learn more information about these diseases and hopefully, eventually, we can fix it.”

[Learn more about the Genetics of FTD in Diverse Populations Study](#)



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