

# TOPAZ NEWSLETTER

TRIAL OF PARKINSON'S AND ZOLEDRONIC ACID

## WINTER 2022 ISSUE:

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**Dr. Kenneth Lyles**

## A Message from Dr. Kenneth Lyles, TOPAZ Study Medical Safety Officer

It is my pleasure to be the Medical Safety Officer and study investigator for this important study to prevent falls and fractures in patients with Parkinson's Disease and Parkinsonism.

For the past 30 years, I have been a specialist in geriatric medicine and bone diseases, a researcher, and a Professor of Medicine at Duke University and the VA Medical Center. Working with patients who have bone diseases, such as osteoporosis, has been one of the most rewarding parts of my career as a physician. I have many patients that I have treated for 10-20 years, and I highly value the relationships we develop. I was involved in the early clinical trials of zoledronate, the treatment we are studying in TOPAZ, and am therefore very familiar with this medication. It is one that I prescribe to my patients to treat osteoporosis and prevent fractures.

I was very excited to join my colleagues Dr. Steven Cummings, an expert in bone health and aging from Sutter Health, and Dr. Caroline Tanner, a neurologist and Parkinson's disease expert at UCSF, in launching the TOPAZ Study. The study team regularly consults with me on medical questions that come from study participants or those who are considering joining the study.

I would like to thank TOPAZ participants in joining the effort to answer important questions about the prevention of fractures and falls in those with Parkinson's Disease and Parkinsonism. We cannot answer important research questions without your participation and contributions to science.

- *Dr. Lyles recently gave a presentation on Bone Health and Parkinson's disease as part of the Parkinson's Foundation Expert Briefing Webinar series. Click [here](#) to view it.*

## TOPAZ PARTICIPANT SPOTLIGHT

### How did you hear about the TOPAZ study?

"I am part of 23andMe research community and received an email from them describing the study."

### What motivated you to join the TOPAZ study?

"I am also part of Parkinson's Progression Markers Initiative (PPMI) and 23andMe research studies. I figure that since I have the disease, I should do everything possible to help science and advance our understanding of the disease. I also have osteopenia. I thought if I did get placed into the group that receives the study drug [zoledronate], the drug would be helpful for my bones."



**Phyllis Chin,  
Research Participant**

### **How did you enroll in TOPAZ?**

"I went to the study website to enroll. There was also a phone number on the website that I called to talk to someone about the study. After enrolling, the study team reached out to me to set up the nurse home visit."

### **How would you describe your experience with the nurse's visit to your home?**

"The nurse was fabulous. She was a lovely person and very efficient. We live in a rural area in California where there were no TOPAZ nurses available. However, we were planning on a trip to Brooklyn, NY to visit my son, and the study team was able to coordinate the nurse visit to take place while I was in Brooklyn. We had no concerns about safety, and the nurse took all the precautions related to COVID-19 pandemic."

### **How was your experience with the administration of the study treatment?**

"The treatment was a 45-minute infusion. During this time, the nurse and I had interesting conversations. I even got to interact with my grandkids during the infusion and the time flew by quickly. I felt fine during and after the infusion. I recall maybe having a very mild ache in the arm couple days later that resolved quickly. There was no worsening in my Parkinson's symptoms."

### **Have you had any fractures or falls related to Parkinson's disease?**

"I have tripped a couple times but not had actual falls or fractures. I had previously read something about higher risk of fractures in people with Parkinson's disease before. After learning about the TOPAZ study, the higher risk of fractures in those with parkinsonism became more real to me."

### **How would you describe your overall satisfaction with the study?**

"I was very satisfied with the whole process."

## **Preventing Falls: Advice from a Physical Therapist**

Falls are a significant issue in people with Parkinson's Disease (PD) that can result in increased disability, decreased quality of life and fractures. People with PD can have difficulties with their balance. Because of this, finding ways to improve balance or ways to increase safety is very important.

If you are diagnosed with PD and have not noticed any changes in your balance, some things you can do to improve your balance and slow the changes from PD is to exercise. A multifaceted program that includes aerobic exercise, strengthening, flexibility and balance and agility is recommended. Working on multi-joint movements, adding turns and pivots, tai chi, yoga, dance, and group exercise classes can be effective ways to challenge your balance. Continuing to engage in your previous hobbies and recreational activities is also important. It's never too early to meet with a physical therapist who can examine your balance and advise you in an appropriate balance program to get you started.

If you have noticed changes in your balance and ability to engage in your activities, ask your neurologist or primary care physician for a physical therapy referral. Balance is very complex so having a physical therapist diagnose your balance problems and recommend the right program for you is important in finding the correct exercises and right level of challenge. Developing a relationship with a physical therapist who can see you over time to reassess your balance and update your program or recommend devices for safety is important in the management of PD.



**Laura Plummer, PT, DPT, MS, NCS**

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# Educational Resources



## Helpline

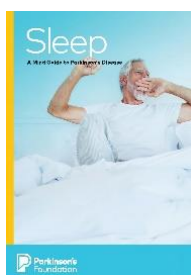
Our Parkinson's disease (PD) information specialists provide up-to-date information about Parkinson's, emotional support and referrals to health professionals and community resources.

Call **1-800-4PD-INFO (473-4636)**

or Email [Helpline@Parkinson.org](mailto:Helpline@Parkinson.org)

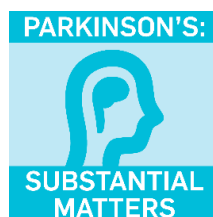
## Publications

Our well-respected educational book series focuses on critical PD issues. Order a free copy of any publication, ranging from introductory information to in-depth material on important topics or read them online. Visit [Parkinson.org/Store](http://Parkinson.org/Store).



## Podcast

Hear directly from Parkinson's experts in our podcast series, *Substantial Matters: Life and Science of Parkinson's*. Learn about the treatments and techniques that can help you live a better life now, as well as the research that can bring a better tomorrow. Visit [Parkinson.org/Podcast](http://Parkinson.org/Podcast)



## Webinars

Participate live or watch an archived *Expert Briefing* webinar to learn more about Parkinson's symptoms, progression, treatments and management.

Visit [Parkinson.org/EB](http://Parkinson.org/EB)

## Online Education

[Parkinson.org](http://Parkinson.org) is the go-to source for Parkinson's information. Articles, videos, fact sheets and more will help you understand the disease, find resources, connect with providers and get involved with the Parkinson's community.

Visit [Parkinson.org](http://Parkinson.org)

## Aware in Care Kit

This free kit has tools and information to help a person with Parkinson's get the best possible care in the hospital, whether it's a planned or emergency visit.

Visit [Parkinson.org/AwareinCare](http://Parkinson.org/AwareinCare)



## Newly Diagnosed Kit

These understandable and actionable resources have the right level of detail for someone newly diagnosed and their care partner to navigate the diagnosis and connect with the Foundation.

Visit [Parkinson.org/NewlyDiagnosed](http://Parkinson.org/NewlyDiagnosed)

Explore these resources at [Parkinson.org/Library](http://Parkinson.org/Library)  
or call **1-800-4PD-INFO (473-4636)**.