

TOPAZ NEWSLETTER

TRIAL OF PARKINSON'S AND ZOLEDRONIC ACID

SUMMER 2021 ISSUE:

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Carlie Tanner, MD, PhD



Steve Cummings, MD

WELCOME TO TOPAZ!

A Message from Dr. Carlie Tanner, TOPAZ Investigator

I am a neurologist at the University of California in San Francisco. My focus is on maintaining health in people with Parkinson's disease.

About five years ago, Dr. Steve Cummings, an internal medicine specialist and an expert in bone health and aging at the San Francisco Coordinating Center, contacted me, because he was observing very high rates of fractures in people with Parkinson's disease. It is well known that patients with Parkinson's have a high risk of falling, but it may not be appreciated that they have a very high risk of suffering a fracture from a fall. In my own clinical practice, I had seen the bad effects of fractures in people with Parkinson's disease. These included reduced mobility, loss of independence, need to live in a care facility and a shortened lifespan. Steve was convinced that fractures could be prevented in many people with Parkinson's disease. We decided to work together to conduct a study that would help us to prove that we can reduce fractures in people with Parkinson's disease. To overcome barriers to care, we developed a study that could take place in the home, testing a single treatment, given once, that would be effective for at least two years. That study is TOPAZ.

We have involved the world's top experts in osteoporosis, zoledronate, and Parkinson's disease, including people with Parkinson's disease and the Parkinson Foundation, to help us develop and conduct the study, and to oversee the safety of people who participant and answer questions.

Thank you for joining TOPAZ. You are providing critical information that will help us to understand more about preventing fractures in Parkinson's disease. We are pleased to meet you and look forward to being in touch over the next several years.

TOPAZ VIRTUAL EVENTS

Please visit the TOPAZ study website: www.topazstudy.org and click on the 'Events' link for announcements about future webinars and other virtual events.

Check out our recently archived webinar on 'Parkinson's Disease and Fractures' to learn more about the latest research from Parkinson's and bone experts. Dr. Carlie Tanner and Dr. Steven Cummings discussed the risk of falls and fractures in those with Parkinson's disease and Parkinsonism, as well as strategies to protect bone health.

TOPAZ PARTICIPANT SPOTLIGHT



Paul Lee, Research Participant

How did you hear about TOPAZ?

“I heard about the study from my neurologist.”

What motivated you to join the TOPAZ study?

“I wanted to pay it forward. I wanted to help other Parkinson’s patients and thought that being in the study may lead to something that would improve their care. I also thought that while I have no broken bones yet, there would be no harm in me getting the study drug since it may be helpful in preventing a fracture in the future.”

How would you describe your experience in the TOPAZ study?

“The overall process has been very easy. After my neurologist told me

about the study, I completed the online consent form, which was easy to follow. I had no concerns whatsoever with the nurse’s visit. She was very professional. I have had a follow up phone call since then. I feel that I have not had to do much for this study, and it has been very convenient.”

Did you experience any side effects related to the study?

“I had no side effects at all.”

How would you describe your overall satisfaction with the study?

“I was very satisfied with the study process and team.”



Christine Cziko, Research Participant

How did you hear about TOPAZ?

“I heard about the study from my neurologist.”

What motivated you to join the TOPAZ study?

“I think that whatever role I can play to help understand this disease is important. My dad had Parkinson’s disease too. I would like to help research find new treatments and ways to improve lives of those living with Parkinson’s disease. If I ended up getting zoledronate, I thought it could help strengthen my bones.”

How would you describe your experience in the TOPAZ study?

This has been an easy study. The online consent process was straightforward. The nurse that came to my home to administer the infusion was terrific, professional, and clear. She was very careful and had all the

equipment in sterile packaging. She knew what she was doing, and the IV insertion was without issues. During the 45 minutes of infusion, I just sat and chatted with the nurse.

Did you experience any side effects related to the study?

I had a mild headache after the infusion but this resolved within 24 hours. I reached out to the TOPAZ study team when I noticed the headache and they called me right away and were reassuring.

How would you describe your overall satisfaction with the study?

“I was very satisfied with the study process and team.”

BOOK REVIEW: “NO TIME LIKE THE FUTURE: AN OPTIMIST CONSIDERS MORTALITY”

The impact of a fracture on Michael J. Fox’s life

In a recent book, Michael describes how a fracture changed his life. He fell in the kitchen, broke his upper arm, and lay on the floor unable to get up or get help. The fracture required surgery. He was wheelchair bound and feeling helpless during months of rehab.

“This is a powerful description of how it feels to lose physical independence. His resilience is inspirational. It reinforces the importance of prevention of devastating fractures. Many people with Parkinsonism are not even aware of their increased risk of fractures.

This is the reason we are testing how to prevent fractures in TOPAZ.”

-Dr. Steven Cummings

