

Letters from SICCA Participants

The following are letters from participants regarding participating in the registry.

I want to thank you and Ava for your warm professionalism in either arranging, conducting and/or performing the exams and procedures in connection with the SICCA Sjogren's International Registry.

When I entered the Medical Center last week it was not without a good measure of apprehension. But with your friendly, concerned and caring guidance that apprehension melted away. Your quiet reassurance of the privacy rights, the purely voluntary aspect of the participation and the thorough explanation of each procedure made the day a breeze.

The biopsy was painless. As I had been told, the stitches were gone by the time I finished dinner. There was some minor bruising to the lower lip but after three days all was normal. As for the drawing of blood, no bruising whatsoever! Quite miraculous given my history of severe bruising following every blood test. Bravo Danielle!

I hope that my participation will help in some small way to speed the diagnosing of Sjogren's. I don't want anyone to have to wait and suffer, like myself, for seven years.

Again, thank you. Being a "guinea pig" was fun!

Participant, California

I wanted to thank you for your outstanding care in the performance of my lip biopsy and removal of a salivary gland cyst. I took one dose of Tylenol after the procedure and 6 months later have only good memories with no memory of associated pain or discomfort. I should note that it is not without some trepidation that I had the procedure done. As a physician, I am uniquely aware of the potential associated risks of the procedure. I was informed by colleagues, that UCSF is quite possibly doing more of these procedures than anyone in the world and that I should go there. Indeed, it was worth the 80 mile commute.

Participant, California

As soon as I could reach the computer I wanted to thank you for everything you and Dr Wu did.

This has been a very good experience. We feel that we have a better understanding of the problem. Talking with all the doctors was very informative for both of us.

The way that you and Dr. Wu talked to the patient in an honest and relaxing way, make us control our nervousness about the experience.

The overall experience was great for us.

Thank you again,

Participant, Mexico City, Mexico

My name is XXX, and I have Primary Sjogren's Syndrome. At 48 years old, I decided to participate in the International Registry called SICCA.

The testing was organized into by specialty. I was first informed of the different processes that would happen that day, and finished my paper work. Danielle Drury answered any questions I had, and drew my blood work. I was introduced to each Medical Staff involved, and had a thorough exam by a Rheumatologist, Ophthalmologist, and Oral Specialist. Dr Ava Wu, DDS performed my lip biopsy. She is an expert in this procedure, and within a few minutes, she was done. I felt no pain, and have had no side effects what so ever.

I recommend being a participant if you have Primary Sjögren's as I believe the more we know, the better we all will feel.

Participant, New Jersey

I really enjoyed working with you and your extraordinarily caring staff- Dr. Wu, the eye doctor, and nurse practitioner (Rheumatology).

Hopefully the research project will be ongoing and successful for future generations to as it has been for me in just being able to participate.

Thank you for all your suggestions to make life less stressful and more peaceful.

My inner lip is healing well. I was able to eat dinner when we arrived home. This morning there was no pain and I believe the stitches are gone.

Participant, California