

Joining the Sjögren's registry: The best decision of my life

By Christine Musil

I was diagnosed with Sjögren's last summer, after the birth of my third child. Confused and a little scared, I looked forward to my first rheumatologist appointment, assuming I'd get answers to my questions. Four appointments and two rheumatologists later, I felt I had more questions than answers and was just as uneasy as I started. One doctor left the room in the middle of a question, apparently indicating our appointment was over. Both doctors insisted that I go on Plaquenil, a mild immunosuppressant, despite telling me I had very "low positives" and mild symptoms. When I questioned the second doctor about this, he replied, "I assume your goal is to live longer?" as if that explained everything.

Frustrated and confused, I turned to the Internet. I found the link to the Sjögren's Registry on the Sjögren's Syndrome Foundation Web site. With a full-time job, twin three-year-olds and an 8-month-old baby, I didn't think I had time to go play human lab rat, but I realized this might be a great opportunity to get what I wanted: answers. I didn't dare to dream I might also find sincerity and compassion.

A few weeks later my husband and I flew to beautiful and historic San Francisco for two days while my parents happily watched the kids. I truly believe it was the best decision of my life.

We started the day with a short cab ride from our charming hotel on Sutter Street to the UCSF Medical Center. Clinical Coordinator Danielle Drury met us in the waiting room and took me to start my adventure, while my husband set off to explore the adjacent Golden Gate Park. After a general Q&A about the Registry, Danielle passed me off to Darlene Young for my rheumatological exam. Often intimidated by my doctors, I found I was very comfortable asking questions in this setting. I asked about Plaquenil, my current symptoms, and things I wasn't even sure were related to my Sjögren's. While she couldn't answer everything, she offered genuine sugges-

tions and didn't leave the room until I assured her I was finished.

Next was the saliva tests with dentist Dr. Ava Wu. This essentially involved spitting into an overgrown test tube every 30 seconds for five minutes. I truly was shocked at how little saliva I produced. Then she attached two little disks to the insides of each cheek to passively measure the parotid gland output. She stimulated my tongue with citric acid (tasted like lemon juice) every 30 seconds for five minutes. I learned that my left parotid produced nothing, even when stimulated, but my right parotid and other glands seem to work pretty well.

During our time together, Dr. Wu asked a variety of questions, many of which had nothing to do with my oral health, and was genuinely interested in my answers. We discussed my migraines, which she told me was a complaint she heard often, and my general medical history. It was so refreshing to talk to someone both intimately familiar with Sjögren's and so sympathetic to all my symptoms.

Before turning me loose for lunch (they gave me \$5 towards my meal), Danielle did a quick blood draw. Okay, I won't lie; it's 13 vials, but because they use a collection tube you don't feel anything once the needle is in place, much like donating blood. Danielle and I chatted through this about kids and family and San Francisco.

After lunch it was back for the most invasive part—the lip biopsy. Dr. Wu told me that people are most afraid of this part, but, honestly, I found it no worse than the blood draw. They do a topical anesthetic before the Novocaine injection, then you feel one slight stick and that's it. They took 10 minor salivary glands from my lower lip, down by the gum line, and gave me two stitches (which fell out in a few days). They sent me off with an ice pack to keep any swelling down. I will add that the stitches were slightly annoying when eating for the next 24 hours, especially when I tried to tackle a very chewy ciabatta sandwich.

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so that the cells will keep producing these messages no matter what hormonal changes are telling them to do. A study using this approach already has been completed with an experimental animal model for Sjögren's syndrome and published in the scientific literature. Again, the results are very encouraging. Alternatively, investigators might be able to mimic the proper cocktails of signals outside the body — in Petri dishes — and use such a system to instruct patients' own immune systems to tolerate their autoantigens. Laboratory experiments continue to validate the basic premises of this possible approach, and work is in progress to develop appropriate models for testing it.

Perhaps somewhat beyond the horizon, there may be hope for patients whose lacrimal glands are not simply quiescent but are so severely damaged that they cannot resume normal functioning even after aggressive autoim-

mune processes are brought fully under control. This hope would be in the new field of tissue engineering, where investigators are taking the first steps toward developing bioartificial lacrimal glands. They appear to have just solved one important obstacle by identifying biocompatible materials that allow lacrimal epithelial cells to grow and organize themselves outside the body in the same way they organize themselves in the body and to perform their normal physiological functions.

Readers of *The Moisture Seekers* may be able to take hope in knowing that they are living in a time of exciting scientific discovery and take some satisfaction in knowing that as members of the Sjögren's Syndrome Foundation and as taxpayers and advocates of support for National Institutes of Health-funded research, they are not just potential beneficiaries, but also active participants, in this era of discovery. 💧

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My last stop was the eye exam with Dr. Jack Whitcher. I learned that my eyes produce more tears than I thought. My regular ophthalmologist had administered a different Schirmer test, applying a topical anesthetic before the test, which yields very different results. The final test involved applying a green dye to stain any dry areas, resulting in the whites of my eyes turning a fairly brilliant green-blue for about 20 minutes. It really shocked my husband when I rejoined him in the waiting room! By the time we caught our cab to the airport, all was normal.

On my incredible, educational, uplifting day at UCSF, I learned that I am not alone in my frustrations. I

learned that there are caring, dedicated professionals working on this disease. I got many answers, suggestions and advice from some of the best medical personnel I have had the privilege to meet. At the end of that day, I felt empowered. Though I am not a doctor or scientist, I was able to do something to help better understand, treat, diagnose and—dare we hope—cure Sjögren's.

We have the power to help ourselves and everyone else with this disease. Take a vacation this year to San Francisco and spend a day at UCSF. It might just be the best decision of your life, too. 💧

For more information about the Sjögren's Registry, visit <http://sicca.ucsf.edu/> or contact Danielle Drury at 415-476-0535.



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