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## Rheum With a View

### Why a Blog About Sjogren's Syndrome?

**Posted By: Robert Fox, Rheumatology, 04:41PM Mar 28**

Sjogren's syndrome is a common rheumatologic condition characterized by dry eyes and dry mouth due to lymphocytic infiltrates. Welcome to a blog that is devoted to the discussion of topics related to this condition. In this initial post, I would like to address the goals of the blog, the reasons I chose to start it, and some basic "rules" of play.

#### Goals of this blog:

- a) Improve diagnosis and therapy for our patients and educate ourselves to the experience of others. We will focus on treatment, as this remains an unmet need. Sjogren's is often the prototype of a "quality of life" disorder. The patient wants to eat with her friends but can't swallow, or the food tastes bitter, while our workup/lab assures them that the disease is stable. There is a basic disconnect between patient complaints and our ability to provide answers in the limited time available. The literature is filled with descriptions of obscure associations and presentations, often to the exclusion of common problems that we face in our patient interactions. To help bridge the gap, I will present patient cases and invite readers to present their own. We invite not only rheumatologists, but ophthalmologists, otolaryngologists, oral medicine specialists and other medical specialists to participate and educate us.
- b) Provide a forum for discussing "academic" topics, including journal articles and interesting presentations at scientific meetings. I call this "immuno-theology", or a discussion about where are we going in terms of pathogenesis and therapy. Too often, these decisions are made in the recesses of academia or industry and do not answer questions that are relevant to practice. This is a good place to speculate on what you would like to see academia or industry address.

#### Why I agreed to "host" a blog:

- a) The underlying cause of Sjogren's syndrome remains unknown, the therapy remains inadequate, and these patients are often seen by a myriad of specialists, each of whom has a different point of view. The net result is often confusion and frustration on the parts of both physician and patient. A blog provides a place for you to either participate by posting your ideas and presenting your cases, or to just sit back and see if the issues apply to your patients. But mostly, it is a place to challenge your assumptions, as I will describe below.
- b) There is a need for each of us to reach outside of our own biases to seek the opinion of others for diagnosis and treatment. Recently, an Op-Ed article by Nicholas Kristoff entitled [The Daily Me](#) appeared in The New York Times. This article got me thinking about how I get my information for Sjogren's syndrome. (Trust me, there is a point to this anecdote). Kristoff's article notes that the "death" of local newspapers will increase the tendency of readers to get their news by grazing the Internet. That, of course, sounds just like me. Although I get my hard copies of standard rheumatology and internal medicine journals, I increasingly use them to locate articles that I found on-line, where I can download them for storage on my computer, in contrast to the old file cabinet full of clipped articles. The key point that Kristoff makes is that we do NOT randomly choose to read articles that we find on-line, since the volume of information is just too great. Therefore, we selectively choose titles, abstracts, and authors that support our pre-existing point of view.

In his article, Kristoff is talking about the views of Republicans vs Democrats: "One classic study sent mailings to Republicans and Democrats, offering them various kinds of political research, ostensibly from a neutral source. Both groups were most eager to receive intelligent arguments that strongly corroborated their pre-existing views. There was also modest interest in receiving manifestly silly arguments for the other party's views (we feel good when we can caricature the other guys as dunces). But there was little interest in encountering solid arguments that might undermine one's own position... The effect is to insulate us further in our own hermetically sealed political chambers... The danger is that this self-selected "news" acts as a narcotic, lulling us into a self-confident stupor through which we will perceive in blacks and whites a world that typically unfolds in grays."

When you stop and think about it, Kristoff's article applies not only to the way we gather political news, but also to the way we get our medical news and formulate our daily treatments. The same group of individuals write the journal articles, review each other's journal submissions, give talks at meetings, and sit on committees that decide what talks or grants should be given. I stand guilty as charged by Kristoff -- I am much more likely to accept some article that agrees with my own preconceptions. **It seems to me that a blog is one of the few ways to break out of this circle.**

#### The rules of the blog:

- a) Enjoy yourself in the pleasure of learning/teaching and help enrich your practice and patient care by sharing with others. As they say on the airline, first put on your own oxygen mask and then put the mask on

#### ABOUT THIS BLOG

A rheumatologist who specializes in Sjogren's syndrome offers a unique perspective on the world of rheumatology.



#### Robert Fox

Dr. Bob Fox received his MD/PhD from Harvard University and Albert Einstein College of Medicine in New York before completing a residency and fellowship at Stanford University. He currently practices in the Scripps-Ximed Medical Group at the University of California San Diego. He serves on the the American College of Rheumatology's Advisory Board for Sjogren's Syndrome and on the Advisory Board of the National Sjogren's Syndrome Foundation.

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children (or adults who act like children). We each went into medicine for the love of science and the chance to help people. Somewhere along the line, the job subtly morphed into filling out forms and acting as referees for seemingly unending crises that sweep the kindergarten of administrators and other office/hospital employees.

This blog is an opportunity for us to return to the love of medicine and science that sustains us throughout the administrative nonsense. **However, this blog will not be a place to complain about administrative or insurance issues but rather to enlighten others about diagnosis and therapy.** It is a place to bring a really interesting article to others' attention, or to express your own experience in agreement or disagreement with published articles. It is a place where you can give yourself a "pat on the back" for a cool diagnosis or treatment. It is a place for medical and intellectual discussion, the reason we chose medicine and why we work such long hours on the patient's behalf.

b) **All entries on the blog will be polite and constructive.**


c) We encourage you to meet others on the blog. Many of us have websites that we established to provide materials for patients or physicians. By listing your websites and emails here, we can create new friendships and provide referral information for our patients who travel. In this spirit, I began constructing a website (robertfoxmd.com) with different folders for published papers, slide presentations, and patient resources. I was determined to have a "noncommercial" website where I could direct patients or referring physicians for more information, instead of just scribbling notes while my nurse grimaced at my lagging time schedule. I will post my slide presentations so that others might use them for their own educational presentations. I only ask that no commercial use of the material is undertaken, and that readers accept that the opinions reflect the bias of the author.

d) Each of us is tremendously overcommitted already, so the last rule of this blog is patience. We have to start somewhere. For example, the development of my website has been slow, often done at night when sleep deprived, and patience is needed by all who access it. But I welcome your suggestions and additions, as well as links to your own websites.

The treatment of Sjogren's rests on three legs: Topical treatment of dry eyes and mouth; b) treatment of extra-articular manifestations; and treatment of poorly defined symptoms often lumped together as "fibromyalgia". We are inadequate in each of these areas, but next week we will start with Topical Therapy and subsequently move through the other subjects. However, we will keep returning to each of these topics as we share experiences, references, and home remedies.

Thanks, and enjoy...

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