

Why you should care about Sjogren's disease

Dear PCP,

This purpose of this letter is to advocate for patients seeking diagnosis and care for [Sjogren's disease](#). I'm a physician living with severe Sjogren's. For so many of us, Sjogren's has a devastating impact on quality of life. Treatments help, but the burden of illness remains high. Even though the disease is quite common, many patients struggle to find a rheumatologist who is engaged and up to date with Sjogren's. Rheumatologists sometimes tell patients that treatments don't work and that nothing can be done. Some rheumatologists are unaware that [Clinical Practice Guidelines for Systemic Manifestations](#) exist. These guidelines were created by Sjogren's experts, under the leadership of the [Sjogren's Foundation](#).

For nearly two decades, I have dedicated myself to becoming highly educated about Sjogren's disease. I teach local physicians, mostly PCPs, about how to recognize Sjogren's and take the first steps to diagnosis. I have learned that most of these PCPs had been taught that Sjogren's is just a sicca syndrome. This outdated notion is compounding the problem for Sjogren's patients who need comprehensive care for this serious multisystemic disease.

My website and blog, [Sjogrens Advocate](#) (www.sjogrensadvocate.com), addresses the gaps in medical education.

- [Sjogren's Neglect](#), a 4-part blog series (Aug-Sep 2019), explains why Sjogren's remains overlooked. **Sjogren's is not rare, just rarely diagnosed!**
- [Sjogren's—Another Look](#) explains the systemic nature of Sjogren's.

PCPs play a key role in both timely diagnosis and ongoing care, especially with an increasing shortage of rheumatologists. Sjogren's is often a life-changing disease. Early treatment is key to reducing progression and preventing complications. Yet, long delays to diagnosis are the norm. Serious organ involvement (30 % plus) and lymphoma (5-10%) may be fatal. All Sjogren's patients should be monitored for complications and comorbidities. I encourage you to explore my website and blog. I expect you will find it eye-opening.

HOW TO GET STARTED:

1. Keep Sjogren's in mind when patients, especially adult women, present with severe unexplained fatigue, widespread pain, or "fibromyalgia."
2. Review the suggestions for how to recognize Sjogren's. See [PCPs: Steps to Diagnosis](#).
3. Learn more about caring [For the Newly Diagnosed](#). Scroll down to the PCP section.
4. Review the [Key Articles](#) for a brief introduction to core clinical concepts.

In addition, I highly recommend these two short introductory videos, [Exploring Sjogren's 1 and 2](#). I welcome your suggestions, comments, and requests!

Sincerely,

Sarah Schafer, MD and Sjogren's patient

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