Notes

About Sjogren's (SHOW-grins)

Sjogren's is a well-characterized disease, <u>NOT</u> a vague syndrome.

Sjogren's is a serious, systemic disease, <u>NEVER</u> "just dryness".

Sjogren's can impact every organ and system in the body; some manifestations of Sjogren's are life-threatening.

Sjogren's is **NOT** rare.

Sjogren's impacts 3-4 million people in the US and is about 3 times as prevalent as lupus.

Sjogren's is invisible.

Most people with Sjogren's look well and may have normal labs even when they are very sick.

Content developed by the Smart Patients Sjogren's group with a special thank you to Smart Patients member, Joel.

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Resources

Sjogren's Foundation Sjogren's Advocate Smart Patients www.sjogrens.org www.sjogrensadvocate.com www.smartpatients.com

How Sjogren's Impacts Me

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The Burden of Sjogren's

Sjogren's is relentless and unpredictable.

New problems can arise **anywhere** in the body at **any time**.

The nervous system, GI tract, lungs, and joints are among the most frequently impacted organs and systems.

Sjogren's is disabling; it's the disease, NOT laziness, that limits what people can do.

Debilitating fatigue and pain often severely impact daily life.

Unlike normal tiredness, fatigue remains a constant challenge, even with adequate sleep and a healthy lifestyle.

Sjogren's is downplayed.

Despite the high burden of disease, it is a struggle to find clinicians with up-to-date knowledge about how to diagnose and manage Sjogren's.

Sjogren's is neglected.

Sjogren's research lags decades behind that of similar diseases, leaving patients without adequate diagnostic tests or treatments.

Sjogren's is costly.

People with Sjogren's are often too sick and fatigued to keep working, and they face endless medical costs.