

## Living with Dryness - The Patient Point of View: Sjögren's Syndrome Survey Results

*In 2009, Ipsos Public Affairs conducted a survey, sponsored by Daiichi Sankyo, Inc. in collaboration with the Sjögren's Syndrome Foundation, of 400 women age 40 years and older residing in the U.S. who have been diagnosed with Sjögren's syndrome. More information about Sjögren's syndrome can be found on [www.livingwithdryness.com](http://www.livingwithdryness.com).<sup>i</sup>*

### Living with Sjögren's Syndrome<sup>i</sup>

#### **Sjögren's syndrome can be a pain...in the mouth.**

- **More than one third** of female Sjögren's syndrome patients said that dry mouth is the most problematic symptom of Sjögren's syndrome they experience.
- **Nearly 60 percent** of sufferers said that they drink at least six glasses of water during an average day which is frustrating for many, as it increases the need to use the restroom and necessitates carrying around water all the time.
- **More than a quarter** said their symptoms made it difficult for them to enjoy kissing.

#### **Life isn't a beach when your mouth tastes like one: living with Sjögren's syndrome can lead to feelings of frustration and isolation.**

- **More than half** of dry-mouth sufferers reported that their symptoms have had a negative impact on their quality of life, and **about half** of dry-mouth sufferers said that their symptoms make them feel different than others.
- Living with Sjögren's syndrome evokes negative emotions for many sufferers, as **almost 50 percent** feel frustrated, almost **one third** feel discouraged and almost **one quarter** feel depressed.
- **Nearly three fourths** of women who suffer from dry-mouth symptoms associated with Sjögren's syndrome said that they feel like few people understand their condition and **about 60 percent** reported that they struggle when describing the severity of their symptoms to others.

### The Diagnostic Journey

#### **Searching for an answer: Years of symptoms can leave patients fed up and frustrated – before they are even diagnosed!**

- **Sjögren's syndrome is often undiagnosed or misdiagnosed** and the average time from the onset of symptoms to diagnosis is **approximately seven years**. A diagnosis is difficult because symptoms may mimic those of menopause, drug side effects, lupus, rheumatoid arthritis, fibromyalgia, chronic fatigue syndrome and multiple sclerosis, and because symptoms can vary from person to person.<sup>ii</sup>
- **More than 50 percent** of patients felt that their diagnostic process was frustrating.
- **One in six** sufferers said that they discussed their symptoms with **five or more** healthcare providers leading up to their diagnosis.
- **Half of sufferers** reported that they were experiencing symptoms for *three or more years* before they were diagnosed. This may be in part due to the difficulty patients have with describing the severity of their symptoms.
- **Nearly three in 10 sufferers** reported that they faced obstacles or complications that delayed their diagnosis.
  - The most common obstacles were seeing several healthcare providers (69 percent), having to undergo tests for various conditions (58 percent), and their healthcare provider dismissing their symptoms (55 percent).

## Talking About Your Symptoms With Your Doctor Until Your Mouth Runs Dry

**Many people – even sufferers themselves – are unfamiliar with Sjögren’s syndrome.**

- **More than 80 percent** of dry-mouth sufferers did not realize that their symptoms can be related to such a serious condition.
- **Two thirds** of dry-mouth sufferers also said that others didn’t believe that their symptoms could have such an impact on day-to-day living.
- **More than 85 percent** of dry-mouth sufferers said that they are hopeful that they can learn how to manage their symptoms, or that they have already learned to do so to minimize their negative impact on their daily life.

---

<sup>i</sup> Ipsos Public Affairs Research. Sjögren’s Syndrome Sufferers Report. 2009.

<sup>ii</sup> Sjögren’s Syndrome Foundation (SSF). <http://www.sjogrens.org/home/about-sjogrens-syndrome/sjogrens-faqs>. Accessed February 11, 2010.