Living with Sjögren’s was conducted by Harris Poll on behalf of the Sjögren’s Syndrome Foundation (SSF), the only non-profit organization focused on increasing research, education and awareness for Sjögren’s, an autoimmune disease that affects the entire body. The purpose of the survey was to gain an understanding from adults ages 18 and older who have been diagnosed with Sjögren’s about the physical, emotional and financial impact of the disease on their lives.

**Sjögren’s Survey Patient Demographic Profile**
The vast majority (96%) of Sjögren's patients who completed the survey were female. About one-third (32%) of respondents were 60 years of age or younger. On average, respondents said they were diagnosed with Sjögren’s over a decade ago (12.3 years mean).

**Most Common Symptoms Experienced**
The vast majority of Sjögren’s patients reported having experienced dry eyes (97%), dry mouth (97%), fatigue (94%), dry or itchy skin (93%), trouble sleeping (91%) and forgetfulness (90%) over the last year. Most said that their dry mouth (92%), dry eyes (92%), and fatigue (80%) symptoms occurred almost weekly or more frequently.

Patients 60 years of age and under said they were more likely than patients over age 60 to experience brain fog (i.e., confusion, forgetfulness, and lack of focus and mental clarity) (66% vs. 53%) and joint pain (67% vs. 62%) almost weekly or more frequently. Patients over 60 years of age reported that they were more likely than patients 60 years of age and under to experience dry nose (65% vs. 59%) and photosensitivity (sunlight) (64% vs. 56%) almost weekly or more frequently.

Half of Sjögren’s patients with severe dryness (53%) also have severe fatigue.
How Sjögren’s Affects Daily Activities

Over 7 in 10 Sjögren’s patients (71%) agreed that their Sjögren’s gets in the way of the things they need to do each day. Most commonly, nearly half (49%) of patients reported Sjögren’s having a great deal or a lot of negative impact on participating in hobbies, social activities, and extracurricular activities. Around a third say it negatively impacts making diet adjustments (35%), performing activities of daily life (34%), traveling or taking a vacation (34%), and overall mood (33%).

Nearly 7 in 10 people living with Sjögren’s (87%) agreed that they struggle to cope with their Sjögren’s. Even more agreed that living with Sjögren’s makes every day a challenge (86%).

How Sjögren’s Adds Up:

- About 7 in 10 Sjögren’s patients (71%) agree that their Sjögren’s gets in the way of the things they need to do each day.
- Over half (59%) say Sjögren’s has a great deal or a lot of negative impact on participating in hobbies, social activities, and extracurricular activities.
- At least three in five (60%) report Sjögren’s negatively impacting making diet adjustments (35%), performing activities of daily life (34%), traveling or taking a vacation (34%), and overall mood (33%).
- Over 7 in 10 Sjögren’s patients (87%) agree that they struggle to cope with their Sjögren’s.
- Over the counter (53%) and prescription (37%) medications and treatments to help with their Sjögren’s symptoms, with an average of over four prescription medications and treatments. Patients living with Sjögren’s for a longer period of time (5-9 years) reported using slightly more treatments than patients living with Sjögren’s for a shorter period of time (0-4 years) (8.7 vs. 8.2 mean).

Changes at Home Due to Sjögren’s

The majority (79%) of Sjögren’s patients surveyed say their disease has led them to make at least one day-to-day change around the house, such as stopping or cutting back on housework (34%) or hiring additional service providers to help with housecleaning or child care (38%).

Visits to a Healthcare Professional

Sjögren’s patients, on average, said they see almost five different healthcare providers (4.6 mean) at least once a year to help manage their disease. Nearly 7 in 10 (86%) of patients surveyed said they see between two and five healthcare providers.

Other Diagnosed Health Conditions

There are many known comorbidities or manifestations of Sjögren’s that can occur in conjunction with the disease. Survey respondents reported having been diagnosed by a health care provider with an average of five other health conditions, including Gastroesophageal Reflux Disease (GERD) (45%), Raynaud’s (38%), Neuropathy (38%), Sinusitis (33%), Hypertension (31%), and Irritable Bowel Syndrome (31%).

Sjögren’s Impact on Speech and Concentration

More than two in five (44%) patients said that Sjögren’s has had a great deal or a lot of negative impact on finding the correct word during conversation. Slightly fewer (40%) said Sjögren’s has had a great deal or a lot of negative impact on concentrating on more than one task at a time (38%) or remembering details at home or work (32%).

Sjögren’s Impact on Sleep

Virtually all patients (97%) reported using eye drops, artificial tears, or non-prescription eye ointments for treatment at some time, while a majority said they have used ibuprofen or other anti-inflammatories (81%), disease-modifying anti-rheumatic drugs (DMARDs) (67%) and CYP or prescription florides (87%), or corticosteroids (92%) for treatment.

Treatments and Medications Used

Today, there is no cure for Sjögren’s, so patients must resort to using a multitude of treatments to help them cope with various symptoms. On average, Sjögren’s patients said they use nearly nine (8.8 mean) medications and treatments to help with their Sjögren’s symptoms, with an average of over four prescription medications or treatments. Patients living with Sjögren’s for a longer period of time (5-9 years) reported using slightly more treatments than patients living with Sjögren’s for a shorter period of time (0-4 years) (8.7 vs. 8.2 mean).

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Changes at Work Due to Sjögren’s

More than half (54%) of Sjögren’s patients surveyed say they have made at least one change regarding work, including having to stop working (38%), reduce their schedule of hours (38%), and make a career change or take a less demanding job (27%) due to their Sjögren’s.

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Impact on Relationships

Sjögren’s patients diagnosed with the disease 0-4 years ago were more likely than those diagnosed with Sjögren’s 5-9 years ago to say their overall mood has been negatively affected by Sjögren’s (44% vs. 36%).

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Financial Impact of Sjögren’s
Two in three (66%) Sjögren’s patients said living with Sjögren’s adds a significant financial burden to their life. Sjögren’s patients 60 years of age and under reported spending more money, on average, on treatments and were more likely than those over 60 to say living with Sjögren’s adds a significant financial burden to their life (72% vs. 63%). When asked how much money they spent on different types of medical expenses in the past 12 months, patients said they spent the most, on average, on dental care followed by prescription medications, and healthcare appointments/co-payments.

Hope for New Treatments
The vast majority (96%) of Sjögren’s patients reported they wish there were additional treatments available. Four-in-five (82%) said that it is extremely important/absolutely essential that new systemic therapies addresses dryness symptoms throughout their body (eyes, mouth, skin, vagina). Respondents also identified the importance of the need for new treatments for fatigue (83%), brain fog/forgetfulness (53%), sleep problems (51%), joint pain or swelling (48%) and muscle pain (43%).

This is Sjögren’s
As many as 4 MILLION AMERICANS have Sjögren’s
with an estimated 2.5 MILLION PATIENTS currently undiagnosed

9 OUT OF 10 Sjögren’s patients ARE WOMEN

It now takes an average of 3 YEARS to receive a Sjögren’s diagnosis

The average age of Sjögren’s diagnosis is 40 YEARS It can occur in all age groups

Frequency appears to INCREASE WITH AGE

About the Survey
Living with Sjögren’s was conducted in the United States using a paper instrument by Harris Poll on behalf of the Sjögren’s Syndrome Foundation between May 11 and July 11, 2016. The research, conducted among 2,962 adults aged 18+ who reported having been diagnosed with Sjögren’s by a medical professional or doctor, examined the variety and severity of experiences Sjögren’s patients have with Sjögren’s and the impact it has on their quality of life. Data was not weighted and therefore represents only the individuals surveyed. Because the sample was based on the individuals from SSF’s database who agreed to participate, it is not possible to estimate a theoretical sampling error.

About the Sjögren’s Syndrome Foundation
The Sjögren’s Syndrome Foundation is the only non-profit organization focused on increasing research, education and awareness for Sjögren’s, one of the most prevalent autoimmune disorders, affecting as many as four million Americans, with an estimated 2.5 million patients currently undiagnosed. For more information, visit www.sjogrens.org or call 1-800-475-6473.