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SIGNIFICANT PHYSICAL AND EMOTIONAL BURDENS OF SJÖGREN'S

MAKE EVERY DAY A CHALLENGE FOR PATIENTS

- *Results from national "Living with Sjögren's" survey demonstrate major impact Sjögren's has on ability to function at home and at work*
- *Patients report seeing an average of five different healthcare professionals annually to help them manage disease*

BETHESDA, MD (March 20, 2017) – For the overwhelming majority of patients living with Sjögren's, an autoimmune disorder affecting more than four million Americans (90% of whom are women), every day is a challenge in coping with the disease, limiting their ability to function at home and in the workplace, according to a recent survey 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.

Nearly 3,000 patients (96% women), aged 18+ years in the U.S. and diagnosed with Sjögren's, shared their experiences with the disease and its physical and emotional effects on their lives in the nationwide *Living with Sjögren's* survey, which was conducted between May 11 and July 11, 2016.

"Sjögren's is a systemic autoimmune disease that affects the entire body," explains SSF Chief Executive Officer Steven Taylor. "Approximately one-percent of the U.S. population, mostly adult women¹, are affected. This is similar to the number of women living with breast cancer.²

"Along with symptoms of extensive dryness, other serious complications such as profound fatigue, chronic pain, organ dysfunction, neuropathies and lymphomas can greatly impair a patient's ability to perform everyday tasks. This research brings to the forefront the significant quality of life challenges faced by Sjögren's patients in trying to live with this often-debilitating disease," he adds.

Around half of patients described dry eyes (54%), fatigue (54%), and dry mouth (50%), the three most commonly reported symptoms of Sjögren's, as having a major impact on their lives in the last year. Seven-in-ten (71%) respondents agreed that their Sjögren's gets in the way of the things they need to do each day. Most commonly, patients reported Sjögren's having a great deal or a lot of negative impact on participating in hobbies, social activities, and extracurricular activities (49%).

The majority (79%) of Sjögren's patients surveyed said 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 (74%) or hiring additional service providers to help with housecleaning or child care (38%). More than half (54%) said they have made at least one change regarding work, including having to stop working (28%), reduce their schedule of hours (28%), and make a career change or take a less demanding job (27%) due to their Sjögren's. Three-in-four patients (74%) said living with Sjögren's also adds a significant emotional burden to their life, having at least some negative impact on relationships with friends and family (63%), sex life (59%), relationships with spouse/partner (55%), and caring for children (19%).

"If you break a bone and wear a cast others can see your injury and understand your limitations," says Taylor. "But with Sjögren's, your symptoms are not clearly visible so not only do you have to put up with challenging, often painful, and sometimes debilitating conditions every day, but you may face disbelief from family, friends, co-workers, and even doctors, who don't understand what's wrong with you."

According to the SSF, an estimated 2.5 million patients are currently undiagnosed and it takes an average of three years to receive a correct diagnosis. "Sjögren's is often undiagnosed or misdiagnosed because disease symptoms frequently overlap or mimic those of menopause, allergies, or medical conditions such as lupus, rheumatoid arthritis, fibromyalgia, and chronic fatigue syndrome," says Nancy Carteron, MD, FACR, Clinical Associate Professor of Medicine at the University of California San Francisco and Chair of SSF's Medical and Scientific Advisory Board.

There are many known comorbidities or manifestations of Sjögren's that can occur in conjunction with the disease. Survey respondents reported having an average of four other health conditions, including Gastroesophageal Reflux Disease (GERD), Raynaud's, neuropathy, sinusitis, hypertension, and irritable bowel syndrome. "Healthcare providers sometimes treat each symptom individually and do not recognize that a systemic disease is present," notes Dr. Carteron.

Rheumatologists have primary responsibility for managing Sjögren's and patients are also seen and treated by ophthalmologists, optometrists, dentists and other specialists depending on their complications. According to the survey, Sjögren's patients, on average, said they see almost five different healthcare professionals (4.6 mean) at least once a year to help manage their disease. Until 2016, no standard of care existed for the management of Sjögren's. The SSF, with the assistance of hundreds of physicians and dentists, developed and published clinical practice guidelines to standardize patient care and give doctors a roadmap of how to treat and manage their Sjögren's patients.

Currently there is no cure for Sjögren's but there are treatments that may improve various symptoms and prevent complications. On average, Sjögren's patients said they use nearly nine medications and treatments (8.8 mean) to help with their Sjögren's symptoms.

The vast majority (96%) of Sjögren's patients reported they wish there were additional systemic therapies available to help treat their symptoms. "Autoimmune diseases such as Sjögren's remain among the most poorly understood and poorly recognized of any category of illness. The Sjögren's Syndrome Foundation is committed to accelerating the development of better diagnostic, management and therapeutics that will have the greatest potential impact on improving the quality of life for Sjögren's patients," says Taylor.

For more information on Sjögren's, visit www.sjogrens.org. A summary of survey findings can be found at www.livingwithsjogrens.org.

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 were 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.

1. Helmick CG, Felson DT, Lawrence RC, et al. National Arthritis Data Workgroup. Estimates of prevalence of arthritis and other rheumatic conditions in the United States, Part I. *Arthritis Rheum.* 2008;58:15-25
2. <http://seer.cancer.gov/statfacts/html/breast.htm>