



Interview with Elaine K. Harris, SSF Founder

Steven Taylor and Elaine Harris at the SSF 30th Anniversary Celebration in 2013

Like many newly diagnosed patients, Elaine K. Harris was frustrated with the lack of information available about her disease. Without a Foundation or the internet, Elaine was only able to find two patient fact sheets that mentioned the disease. Determined to take control of her health and learn more about her symptoms, Elaine used her past community involvement to start a local support group with only one other Sjögren's patient that she met, the secretary of her doctor. She then slowly grew that support group into the Sjögren's Syndrome Foundation (SSF).

Today, the Foundation serves thousands of patients and has grown into a powerhouse organization, breaking down barriers worldwide in the field of Sjögren's. The many achievements that the SSF has seen in the last 35 years is because of the hundreds of volunteers and members across the country. Although none of what we have today would be possible if it wasn't for Elaine turning her frustration into a source of hope for all patients.

This August, Elaine Harris and Janet Church, the new Chairman of the SSF Board of Directors, had the opportunity to meet and discussed the past, present and future of the Foundation. Below are excerpts from their interview.

What was your key motivation as to why you started the Foundation?

I wanted more people to know about Sjögren's, to be able to talk to other patients and have more doctors interested in it.

How do you think the Foundation is doing today?

I think the Foundation is doing superbly.

What was the primary focus of the SSF in its earliest days?

There was a need for doctors who could recognize the discrete manifestations as possibly related symptoms. We wanted to develop and distribute patient-oriented literature that would also help doctors communicate with each other regarding the patient's needs and proposed treatment.

We also saw a great need for promoting public awareness about Sjögren's and getting more physicians interested so that they would focus on developing treatments, bringing relief to patients.

How did the newsletter receive the name, The Moisture Seekers?

Name recognition is a challenge with Sjögren's. It's a disease name that people cannot easily pronounce or spell. We reasoned that since we were looking for moisture for the many organs in our body, naming our group *The Moisture Seekers* made sense.

When we were ready to incorporate as an official "not-for-profit organization," our lawyer suggested it would be best to name the organization after the disease. We decided to become the "Sjögren's Syndrome Foundation" but I didn't want to let the name *The Moisture Seekers* go and retained it for the newsletter.

Why do you think it's important for patients to add their voice to the SSF?

The squeaky wheel gets oiled. Sjögren's patients take time and doctors are often limited with time. This is why it's so important to learn from doctors through the SSF newsletter, local support group meetings and the National Patient Conferences.

It is also important to help educate your doctor and not be bashful when talking about your disease. You

have to spread the word and keep trying for those who are living with debilitating manifestations and find it difficult to function.

What is the best advice that you would give to a new diagnosed patient?

Meet other Sjögren's patients. Patients will talk to each other about some of their problems that they are reluctant to bring up to doctors.

Find a doctor who is informed about the many manifestations of Sjögren's or one who will work with you and is interested in learning. Someone who will listen to your problems, communicate with the other specialists treating you, and keep up with the new medications being developed to treat the disease.

What advice would you like to share with all patients?

Be open about your Sjögren's and never stop reaching!

What is the biggest transformation between the early years of the SSF to now?

Growth in the pharmaceutical industry. Today it seems possible that there's a pot of gold to be found! ■



Elaine K. Harris (center)



Elaine Harris at the 2016 New York City Sip for Sjögren's Event



Janet E. Church
Chairman Sjögren's Syndrome
Foundation Board of Directors

Janet Church has served as a member of the Board of Directors for six years and throughout that time has offered her expertise as an entrepreneur, tech-industry veteran and a Sjögren's patient, a key member and volunteer of the foundation. We are honored to have Janet as the new Chairman of the Sjögren's Syndrome Foundation Board of Directors.

"It was a joy to talk to the woman who has been carrying the patient flag for all of us for the past 35 years. As the new SSF Chairperson and having been diagnosed with Sjögren's for 12 years, I look forward to the many direct patient-to-patient conversations we will have in the upcoming years and promise to do my best to carry the flag!"

For me, I felt that getting involved with the Foundation was a way that I could help myself the most. I feel that it is better to Stay Active, Stay Informed and Attempt to Do Something, than to not do something. I am inspired by all that the SSF has accomplished and I am personally excited, as well as honored, to be leading us over the next two years." ■