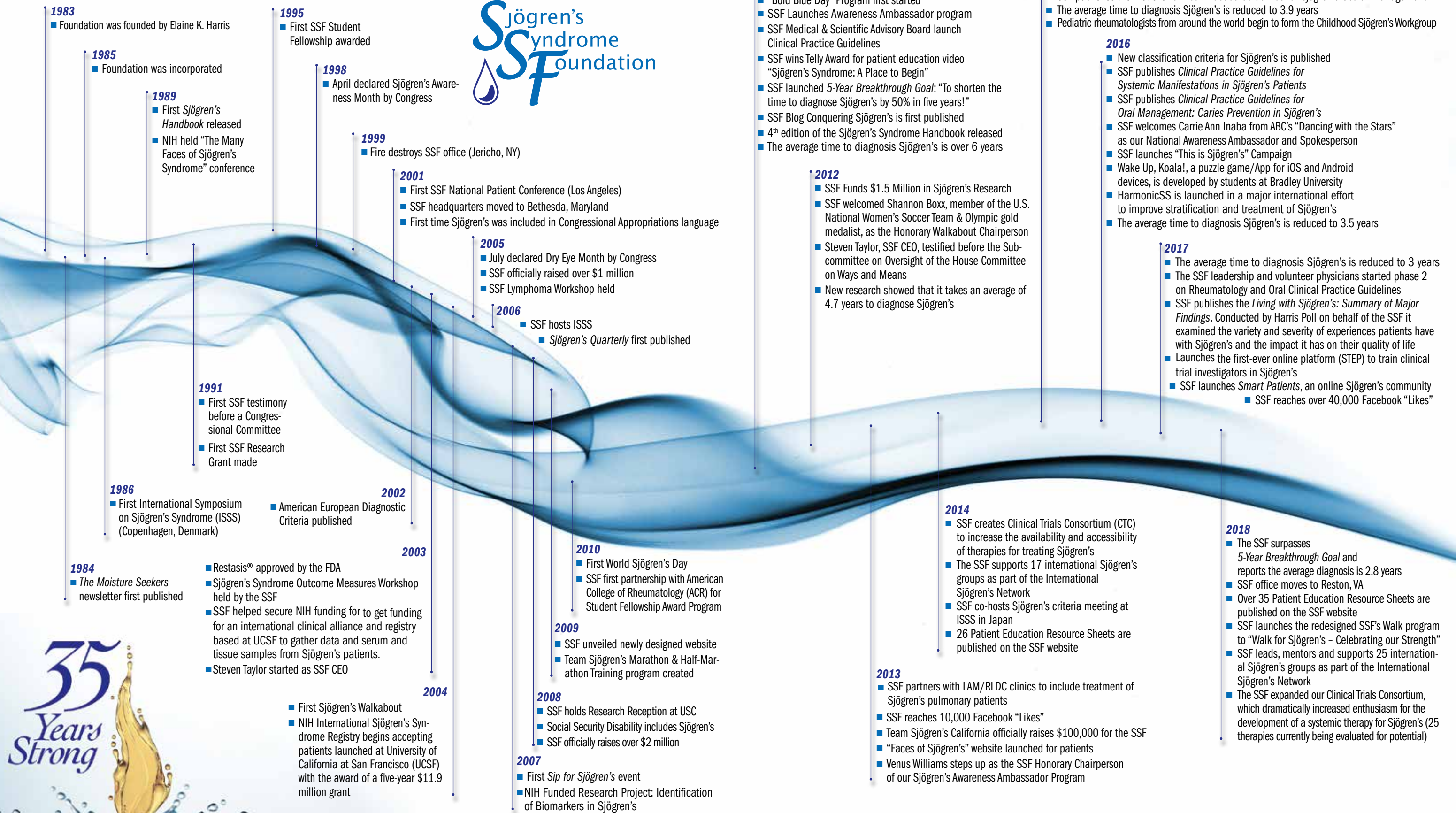


Sjögren's Syndrome Foundation Timeline 1983 – 2018



- 1983**
 - Foundation was founded by Elaine K. Harris
- 1984**
 - *The Moisture Seekers* newsletter first published
- 1985**
 - Foundation was incorporated
- 1986**
 - First International Symposium on Sjögren's Syndrome (ISSS) (Copenhagen, Denmark)
- 1989**
 - First *Sjögren's Handbook* released
 - NIH held "The Many Faces of Sjögren's Syndrome" conference
- 1991**
 - First SSF testimony before a Congressional Committee
 - First SSF Research Grant made
- 1995**
 - First SSF Student Fellowship awarded
- 1998**
 - April declared Sjögren's Awareness Month by Congress
- 1999**
 - Fire destroys SSF office (Jericho, NY)
- 2001**
 - First SSF National Patient Conference (Los Angeles)
 - SSF headquarters moved to Bethesda, Maryland
 - First time Sjögren's was included in Congressional Appropriations language
- 2002**
 - American European Diagnostic Criteria published
- 2003**
 - Restasis® approved by the FDA
 - Sjögren's Syndrome Outcome Measures Workshop held by the SSF
 - SSF helped secure NIH funding for to get funding for an international clinical alliance and registry based at UCSF to gather data and serum and tissue samples from Sjögren's patients.
 - Steven Taylor started as SSF CEO
- 2004**
 - First Sjögren's Walkabout
 - NIH International Sjögren's Syndrome Registry begins accepting patients launched at University of California at San Francisco (UCSF) with the award of a five-year \$11.9 million grant
- 2005**
 - July declared Dry Eye Month by Congress
 - SSF officially raised over \$1 million
 - SSF Lymphoma Workshop held
- 2006**
 - SSF hosts ISSS
 - *Sjögren's Quarterly* first published
- 2007**
 - First *Sip for Sjögren's* event
 - NIH Funded Research Project: Identification of Biomarkers in Sjögren's
- 2008**
 - SSF holds Research Reception at USC
 - Social Security Disability includes Sjögren's
 - SSF officially raises over \$2 million
- 2009**
 - SSF unveiled newly designed website
 - Team Sjögren's Marathon & Half-Marathon Training program created
- 2010**
 - First World Sjögren's Day
 - SSF first partnership with American College of Rheumatology (ACR) for Student Fellowship Award Program
- 2011**
 - "Bold Blue Day" Program first started
 - SSF Launches Awareness Ambassador program
 - SSF Medical & Scientific Advisory Board launch Clinical Practice Guidelines
 - SSF wins Telly Award for patient education video "Sjögren's Syndrome: A Place to Begin"
 - SSF launched *5-Year Breakthrough Goal*: "To shorten the time to diagnose Sjögren's by 50% in five years!"
 - SSF Blog Conquering Sjögren's is first published
 - 4th edition of the Sjögren's Syndrome Handbook released
 - The average time to diagnosis Sjögren's is over 6 years
- 2012**
 - SSF Funds \$1.5 Million in Sjögren's Research
 - SSF welcomed Shannon Boxx, member of the U.S. National Women's Soccer Team & Olympic gold medalist, as the Honorary Walkabout Chairperson
 - Steven Taylor, SSF CEO, testified before the Subcommittee on Oversight of the House Committee on Ways and Means
 - New research showed that it takes an average of 4.7 years to diagnose Sjögren's
- 2013**
 - SSF partners with LAM/RLDC clinics to include treatment of Sjögren's pulmonary patients
 - SSF reaches 10,000 Facebook "Likes"
 - Team Sjögren's California officially raises \$100,000 for the SSF
 - "Faces of Sjögren's" website launched for patients
 - Venus Williams steps up as the SSF Honorary Chairperson of our Sjögren's Awareness Ambassador Program
- 2014**
 - SSF creates Clinical Trials Consortium (CTC) to increase the availability and accessibility of therapies for treating Sjögren's
 - The SSF supports 17 international Sjögren's groups as part of the International Sjögren's Network
 - SSF co-hosts Sjögren's criteria meeting at ISSS in Japan
 - 26 Patient Education Resource Sheets are published on the SSF website
- 2015**
 - SSF publishes the first ever *Clinical Practice Guidelines for Sjögren's Ocular Management*
 - The average time to diagnosis Sjögren's is reduced to 3.9 years
 - Pediatric rheumatologists from around the world begin to form the Childhood Sjögren's Workgroup
- 2016**
 - New classification criteria for Sjögren's is published
 - SSF publishes *Clinical Practice Guidelines for Systemic Manifestations in Sjögren's Patients*
 - SSF publishes *Clinical Practice Guidelines for Oral Management: Caries Prevention in Sjögren's*
 - SSF welcomes Carrie Ann Inaba from ABC's "Dancing with the Stars" as our National Awareness Ambassador and Spokesperson
 - SSF launches "This is Sjögren's" Campaign
 - Wake Up, Koala!, a puzzle game/App for iOS and Android devices, is developed by students at Bradley University
 - HarmonicSS is launched in a major international effort to improve stratification and treatment of Sjögren's
 - The average time to diagnosis Sjögren's is reduced to 3.5 years
- 2017**
 - The average time to diagnosis Sjögren's is reduced to 3 years
 - The SSF leadership and volunteer physicians started phase 2 on Rheumatology and Oral Clinical Practice Guidelines
 - SSF publishes the *Living with Sjögren's: Summary of Major Findings*. Conducted by Harris Poll on behalf of the SSF it examined the variety and severity of experiences patients have with Sjögren's and the impact it has on their quality of life
 - Launches the first-ever online platform (STEP) to train clinical trial investigators in Sjögren's
 - SSF launches *Smart Patients*, an online Sjögren's community
 - SSF reaches over 40,000 Facebook "Likes"
- 2018**
 - The SSF surpasses *5-Year Breakthrough Goal* and reports the average diagnosis is 2.8 years
 - SSF office moves to Reston, VA
 - Over 35 Patient Education Resource Sheets are published on the SSF website
 - SSF launches the redesigned SSF's Walk program to "Walk for Sjögren's - Celebrating our Strength"
 - SSF leads, mentors and supports 25 international Sjögren's groups as part of the International Sjögren's Network
 - The SSF expanded our Clinical Trials Consortium, which dramatically increased enthusiasm for the development of a systemic therapy for Sjögren's (25 therapies currently being evaluated for potential)