

# The Moisture Seekers

Sjögren's Syndrome Foundation



www.sjogrens.org

# 30 Years

Volume 31, Issue 8

September 2013

f SjogrensSyndromeFoundation

@MoistureSeekers

## The Sjögren's Syndrome Foundation 30th Anniversary

Everyday I am fortunate to get phone calls, emails and letters from patients and their family members thanking me for the Sjögren's Syndrome Foundation. And thankful for what we do to change the lives of patients!

But it's not me who they should be thanking. It is our thousands of volunteers, our physicians, our Board of Directors as well as all of you—our members—who help to increase awareness, share your story and continue to support the SSF through your donations and volunteer hours.

As I look back over the past 30 years of the Foundation, I am humbled to be able to say that I personally know Elaine Harris, the pioneer and founder of the SSF who stepped out on a limb to start the SSF back in 1983. Without her willingness to launch the SSF and her dedication in making sure that the SSF information reached across the country—none of our success would be happening today.

Now let's look back to 1983! There was no internet. There were no computers. Just Elaine Harris sitting in her kitchen using her handwritten notes and her typewriter to send letters to fellow patients, physicians and companies to encourage them to develop products for all Sjögren's patients. Elaine didn't have the benefit of the internet or email to help spread the word and for this, every Sjögren's patient should be grateful to her for setting the stage for what the SSF has become today!

*continued page 2* ▼



*Evolution of The Moisture Seekers newsletter from top to bottom: 1984, 1990, 1998 and 2002*



### In This Issue

3 I Stood Up

5 Henrik Sjögren

8 SSF Timeline

10 Memorial & Honor

13 Breakthrough Bullet



Founded by  
Elaine K. Harris in 1983

### Board of Directors

#### Chairman of the Board

S. Lance Forstot, MD

#### Chairman-Elect

Kenneth Economou

#### Treasurer

Kathryn P. McCarren

#### Secretary

Pamela S. Brown

#### Immediate Past Chairman

Lynn M. Petruzzi, RN, MSN

Estrella Bibbey

Michael T. Brennan, DDS, MHS

Steven E. Carsons, MD

Nancy L. Carteron, MD, FACR

Janet E. Church

Stephen Cohen, OD

Jack Faricelli

Denise Faustman, MD, PhD

Theresa Lawrence Ford, MD

Mary W. McNeil

Shari Rood

Vidya Sankar, DMD, MHS

### Medical & Scientific Advisory Board

#### Chairman

Denise Faustman, MD, PhD

Richard Brasington, MD

Steven E. Carsons, MD

Troy E. Daniels, DDS, MS

H. Kenneth Fisher, MD, FACP, FCCP

Gary Foulks, MD, FACS

Philip C. Fox, DDS

Tara Mardigan, MS, MPH, RD

Austin K. Mircheff, PhD

John Daniel Nelson, MD, FACS

Kelly Nichols, OD

Athena Papas, DMD, PhD

Ann Parke, MD

Andres Pinto, DMD

Nelson L. Rhodus, DMD, MPH

Daniel Small, MD, FACP

Neil I. Stahl, MD

Pamela Stratton, MD

Frederick B. Vivino, MD, FACR

#### Chief Executive Officer

Steven Taylor

#### Director of Marketing

Elizabeth Trocchio

e-mail: [tms@sjogrens.org](mailto:tms@sjogrens.org)  
[www.sjogrens.org](http://www.sjogrens.org)

"30 Years" continued from page 1 ▼

Now what is most exciting is the SSF is at the tipping point for remarkable progress. Never before has Sjögren's been at such a point where amazing breakthroughs in the development of new therapies as well as new diagnostics for Sjögren's are on the horizon. We have never seen such an interest from the pharmaceutical industry to ensure that Sjögren's patients have the proper treatments available to help them with their symptoms as well as their overall disease.

In addition, the SSF is most excited to be finalizing the first draft of our clinical practice guidelines, a document that will give treating physicians a roadmap for how to treat, monitor and manage their Sjögren's patients. These guidelines will mark the first time ever in the history of our disease that such a document will exist. Talk about exciting times!

As always, we need your continued support. These breakthroughs and advancements cannot happen without the SSF leading the way and ensuring progress is still being made on all fronts. Your support by sharing your story, telling others about the SSF, attending our events, volunteering your time or donating to the SSF all makes a difference!

The momentum is on our side. Now, just imagine what the SSF will be able to accomplish in the next 30 years!



Chief Executive Officer



30  
Years

The Moisture Seekers® Newsletter is published by the Sjögren's Syndrome Foundation Inc., 6707 Democracy Blvd., Ste 325; Bethesda, MD 20817. Copyright ©2013 Sjögren's Syndrome Foundation Inc. ISSN 0899-637.

DISCLAIMER: The Sjögren's Syndrome Foundation Inc. in no way endorses any of the medications, treatments, or products mentioned in advertisements or articles. This newsletter is for informational purposes only. Readers are advised to discuss any research news, drugs, treatments or products mentioned herein with their health care providers.

# I Stood Up...

*Elaine K. Harris*  
 Founder of the Sjögren's  
 Syndrome Foundation



Like many newly diagnosed patients, Elaine Harris was frustrated with the lack of information available about the disease that was making her feel so miserable. 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 who she met, the secretary of her doctor. She then slowly grew that support group into the Sjögren's Syndrome Foundation that now serves thousands of patients worldwide, helping educate patients, physicians and the general public about this debilitating disease.

Today, the SSF is thankful to have dedicated volunteers across the country who stand up for Sjögren's every day. Our Board of Directors, event committees, awareness ambassadors and support group leaders all donate their time to help us conquer Sjögren's. Although none of what we have today would be possible if it wasn't for Elaine turning her frustration into the powerhouse organization that we are today and stepping up for all patients.

Here is an archived interview from Elaine in 2008 where she reflected back on her journey with Sjögren's.

## *What was the primary focus of the Foundation in its earliest days?*

One of our first goals was to identify physicians and dentists who were knowledgeable about Sjögren's. We saw a need for doctors who could recognize the discrete manifestations (e.g., dry eyes, hurt-all-over feeling, an unusual amount of fatigue, dry mouth, excessive dental plaque, nosebleeds, swollen glands, and vaginal dryness) as possibly related symptoms. Once these physicians were identified, we began to refer patients to them.

We also 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.



Finally, we 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.

## *What were some of the biggest challenges you encountered as a new and upstart organization?*

Name recognition was a major challenge. Sjögren's is not a name that people could 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.

*"I Stood Up" continued from page 3 ▼*

Two years after our first meeting we were ready to incorporate as an official "not-for-profit organization." By then we had a highly regarded newsletter and a growing reputation. Our lawyer suggested it would be best to name the organization after the disease, and so we became the "Sjögren's Syndrome Foundation" but retained *The Moisture Seekers* name for our increasingly popular newsletter.

### *What is your impression of the Foundation as it is today?*

I am very pleased and proud. I think Steven Taylor and his staff are doing a wonderful job. I particularly like the two-day National Patient Conferences that are taking place.

### *What one piece of advice would you give a recently diagnosed Sjögren's patient?*

Find a doctor who is informed about the many manifestations of Sjögren's. Someone who will listen to your problems, will "manage" your symptoms, communicate with the other specialists treating you, and keep up

with the new medications being developed to treat the disease. Also, speak with members of your local support group to learn about local doctors.

### *What's the best advice that you ever received as a Sjögren's patient?*

Way back in 1982 when my doctor told me that there was nothing he could do for me, that I just had to "learn how to live with it." I ran out of his office crying. In order to learn how to live with Sjögren's I had to become an informed patient. It wasn't easy because there was no SSF, or even a local support group, no newsletter, no Sjögren's Syndrome Handbook. It was the absence of these resources that provided the stimulus to develop such resources, leading to my forming a local Long Island support group which evolved into the SSF.

Today the best way to become an informed patient and learn how to live more comfortably with Sjögren's, you really need to belong to the SSF and continue to support it throughout your lifetime. With our support, the SSF can continue its work to spread knowledge about diagnosis and treatments to health professionals and support research to find the cause and hopefully, some day, a cure. ■

## **IT'S TIME**

### **United Way • Combined Federal Campaign • State Payroll Deduction**

Each fall your local United Way, Combined Federal Campaign, state employee, and private employer payroll deduction campaigns begin. We hope you will remember the Sjögren's Syndrome Foundation when choosing where to allocate your donation. (CFC #10603)

If we are not listed on the contribution form, you usually may write in the Sjögren's Syndrome Foundation.

Tell your co-workers, friends, and family members how important it is to choose and write in the Sjögren's Syndrome Foundation on their campaign form, too.

If your employers will not allow you to write in the Sjögren's Syndrome Foundation, remind them that we are a national non-profit 501(C3) organization and qualify for most payroll deduction campaigns. If they need more information, please contact the Foundation at 800-475-6473 and ask for Elizabeth Trocchio.

#### **Just think – every dollar counts.**

Last year alone – thanks to those who chose to give through their employer's payroll campaign – the Sjögren's Syndrome Foundation was able to increase its Research and Awareness commitments.

#### ***Remember, the Foundation has received the:***



# Henrik Sjögren

## A Medical Historical Presentation

by Magnus Carlsson, Department of Medicine, County Hospital Ryhov, Jonkoping, Sweden



Henrik Sjögren is among the most internationally well-known Swedish physicians. This of course relates to the eponym “Sjögren’s syndrome,” but this famous ophthalmologist actually achieved much more.

Sjögren was born in July 1899 as the second child of three

in the small city of Koping, located at Lake Malaren some 150 km west of Stockholm. His father, Conrad Johansson, was a merchant and his mother, Emilie Sjögren, after whom he took his last name, was a woman with extraordinary political and social interest. His social background was bourgeois and his childhood bright.

The family had a great interest in music and reading and Henrik began studies on the piano from an early age. This musical interest became his main hobby throughout

life; he became a skilled pianist, even composing some small works.

There was no earlier tradition of medicine in his family. His older brother began medical studies but, sadly, died very young of the Spanish flu. It is uncertain in what sense these circumstances had influence on Henrik Sjögren’s choice of profession. After graduating from high school in the nearby city of Vasteras in 1918, he completed military service in Skelleftea in northern Sweden.

### Medical education

In 1919, at the age of twenty, Henrik Sjögren started his medical education at the Karolinska Institute in Stockholm. He fell in love with a classmate, Maria Hellgren, daughter of a late, distinguished ophthalmologist in Stockholm. They were engaged in 1921 and married in 1928. Sjögren’s studies were successful and he made an early choice of specialty, the same as his fiancée, who, like her father, became an ophthalmologist. In 1925, before finishing his studies, Sjögren periodically worked as an assistant surgeon in the Eye Clinic at Serafimer Hospital in Stockholm. He eventually gained permanent employment there and in 1927 received his medical doctorate.

continued page 6 ▼

“Around-the-Clock Relief From Dry Mouth”

MedActive

## Lozenges, Sprays & Gel

Designed to meet the needs of Sjögren’s patients

Now available at your local  
Independent Pharmacy

 Proudly Made in the U.S.A.

[www.medactive.com](http://www.medactive.com) 1-866-887-4867



*“Henrik Sjögren” continued from page 3 ▼*

### “Svenskbyborna” (The Swedish immigrants)

In 1929, Henrik and Maria Sjögren were asked by the Royal Swedish Medical Board to examine a very special group of immigrants, in Swedish called “Svenskbyborna.” When Sweden was a great power, these immigrants’ ancestors had lived on the isles outside today’s Estonia. After a war defeat they became Russian citizens and in the 1780s they were forced to leave their homes for ‘no man’s land’ in the Ukraine. For generations they tried to emigrate to Sweden but in vain until the year 1929. With the aid of the Swedish Red Cross they were initially placed in military barracks in the city of Jonkoping.

Some immigrants suffered from trachoma, and the task of examining and treating them periodically brought the Sjögren couple to Jonkoping during that year. It is an interesting fact that Mrs. Sjögren, used to the busy life in Stockholm, found the city of Jonkoping boring. She would later live there for more than 30 years.

### The “sicca-syndrome”

In 1929 Henrik Sjögren met a patient who complained of dry eyes, dry mouth and pain from several joints. Each of these symptoms was already well-known, but it was the combination of them together that Sjögren noticed. However, he was not the very first to put these symptoms together. A French ophthalmologist, Henri Gougerot, had published the same observation in 1926.

Sjögren continued his work at Serafimer Hospital until 1931, when he received an appointment at the Eye Clinic at Sabbatsberg, another hospital in Stockholm. There he performed most of his work in collecting cases with the diagnosis “keratoconjunctivitis sicca,” a name invented by Sjögren in a publication from 1930.

He made very careful examinations, which included microscopic views and excellent photos of lacrimal and salivary glands, conjunctiva and corneas.

### The doctoral dissertation

In May 1933 he defended his doctoral thesis, entitled “Zur Kenntniss der Keratoconjunctivitis Sicca.” It presented 19 cases and consisted of both clinical and pathological sections. There was much enthusiasm but also criticism, and he received mediocre credit. On a scale of marks from 1-3, Sjögren received a 1.5. This was too low to become a “docent” (associate professor) and as a result, his academic career came to an end. With today’s knowledge, it can be said that much of the criticism was wrong and unfair. Sjögren – like many other pioneers – was ahead of his time.

He continued his clinical work at Sabbatsberg Hospital until 1935 and left as a skilled ophthalmologist. His main interests were lacrimation and corneal diseases.

### The Jonkoping period

In 1935 Henrik and Maria Sjögren moved to Jonkoping. The reasons for their move are not clear, but most likely it was due to a combination of promising possibilities. A separate Eye Clinic was to be built, and Sjögren was given great influence on its construction and equipment.

January 1, 1938 he was appointed hospital surgeon to the new Eye Clinic. This was the start of an almost 30-year long era of outstanding work, both clinical and scientific. He was the only ophthalmologist until an assistant surgeon was appointed in 1954. His wife Maria had a practice at home with the possibility to perform operations one day a week.

Henrik Sjögren was a good clinician and also became famous as a good teacher for younger colleagues. Many ophthalmologists attended the clinic, and many of those had later brilliant careers and pointed to Sjögren’s influence.

### The international career

The eponym “Gougerot-Sjögren’s disease,” which appeared in the literature in the 1930s, was a decade later reduced to “Sjögren’s disease.” This was due to Sjögren’s continuous and deep interest in this condition. He reported on many cases and was surpassed in number only by the Mayo Clinic in Rochester, Minnesota.

In 1943, Bruce Hamilton, an ophthalmologist in Hobart, Australia, translated Sjögren’s thesis from German to English. A preface and an appendix were added. Australian ophthalmologists had an intense interest in the use of contact lenses. This interest was connected to the knowledge of lacrimation and, more important, lacrimal dysfunction – the “sicca-syndrome.” Thus, an English version of Sjögren’s thesis was needed.

In 1951, Henrik Sjögren was invited as guest lecturer at the Royal Australian College of ophthalmologists. The main goal was an eye congress in Hobart, with Professor Hamilton as chairman. On this occasion, Sjögren was awarded an honorary membership in the college. On his route, which took him around the globe, he met and discussed with colleagues in several countries such as Egypt, Pakistan, India, Singapore, Australia, New Zealand and the USA. There is no doubt that Henrik Sjögren already had a great international reputation.

### The Swedish career

Sjögren was a great clinician with broad clinical experience. In acknowledgement of his work and international renown, the “docent” title was bestowed on him

in 1957 from the University of Gothenburg, and in 1961 the Swedish government granted him the title "Professor." This could perhaps be looked upon as a personal revenge for his less successful dissertation and its consequences. However, this was not the case. Sjögren, in spite of his fame, is described by many as a very humble person and by some even as shy.

Besides his clinical activity, he was also an innovator in ophthalmology. Perhaps his most important contribution was his invention of a special pair of tongs used in corneal transplantation. An operation of this kind was recorded by the Swedish Radio & Television Company and broadcast in 1961 as one of the first live medical operation movies in this country.

Henrik Sjögren retired in 1967 at 68 years old. He and his wife moved to Lund where he enjoyed the nearness of the university library.

### Conclusion

Henrik Sjögren could have been just an ophthalmologist who happened to meet a patient with dry eyes. Instead, his wide-open mind led him to the discovery of an unknown clinical entity, later named after him. Sjögren did not know the aetiology. Today we know Sjögren's syndrome is a complex immunologically-based disorder.

Sjögren received international credit for his discovery. In 1970 he became an honorary member of the American Rheumatism Association, and in 1976 he became a member of the Royal College of Physicians and Surgeons in Glasgow. That same year he was also appointed an honorary member of the Swedish Rheumatological Society.

### In memory

Henrik Sjögren died in 1986 and his wife Maria in 1991. He is buried beside his wife and her parents on Norra Begravningsplatsen in Solna, Stockholm. This cemetery has become a correspondence to well-known Cimetiere Pere-Lachaise in Paris and is the burial spot for many famous people. The simple grave in this prestigious cemetery is a last sign of his modesty. ■



## IS YOUR NOSE DRY? IRRITATED? PAINFUL?

*Your Relief is Here!*

INTRODUCING

# GeloNasal®

DRY NOSE RELIEF

When the mucosa of your nose is dry and irritated, it can be very uncomfortable and even painful. GeloNasal Dry Nose Relief is here!

GeloNasal is a superior alternative to saline nasal sprays, lasting nine times longer for at least **three hours of dry nose relief.**

GeloNasal delivers gentle and effective dry nose relief for even the driest noses.

GeloNasal is available for purchase online at [www.gelonasal.com](http://www.gelonasal.com) and at select retail pharmacies.



Use this code at [gelonasal.com](http://gelonasal.com) to receive **\$4.00 OFF your first purchase: SSFMS**

Sjögren's Syndrome Foundation  
*Legacy of Hope*



If you would like to receive information on how you can *Leave a Legacy* to support the Sjögren's Syndrome Foundation's critical research initiatives or to support one of our many other programs, please contact Steven Taylor at 800-475-6473.

*Leave A Legacy – Remember Us in Your Will*

# Sjögren's Syndrome Foundation Timeline

**1983**

- Foundation was founded by Elaine K. Harris

**1985**

- Foundation was incorporated

**1984**

- *The Moisture Seekers* newsletter first published

**1986**

- First International Symposium on Sjögren's Syndrome (ISSS) (Copenhagen, Denmark)

**1989**

- First *Sjögren's Handbook* written and printed
- 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 Syndrome Awareness Month by Congress

**1999**

- Fire destroys SSF office (Jericho, NY)

**2001**

- First SSF National Patient Meeting (Los Angeles)
- SSF headquarters moved to Bethesda, Maryland
- First time Sjögren's syndrome was included in Congressional Appropriations language

**2002**

- American European Diagnostic Criteria published

30 Years **SSF** Sjögren's Syndrome Foundation

HIGHLIGHTS FROM  
1983-2013



## 2003

- Restasis® approved by the FDA
- Sjögren's Syndrome Outcome Measures Workshop held sponsored by the SSF
- 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

- 75<sup>th</sup> Support Group started
- July declared Dry Eye Month by Congress
- SSF officially raised over \$1 million
- SSF Lymphoma Workshop held

## 2006

- SSF hosts International Symposium on Sjögren's Syndrome (ISSS)
- First Issue of the *Sjögren's Quarterly* published

## 2007

- First *Sip for Sjögren's* event

## 2008

- SSF holds Research Reception at the University of Southern California
- Social Security Disability Guidelines include Sjögren's for the first time
- SSF officially raises over \$2 million

## 2009

- SSF Launches Clinical Trial Consortium
- SSF unveiled newly designed website
- Team Sjögren's Marathon & Half-Marathon Training program created
- "Little Voices" Fight a BIG Disease Program was started

## 2010

- First World Sjögren's Day
- SSF first partnership with the American College of Rheumatology (ACR) for Student Fellowship Award Program

## 2011

- "Bold Blue Day" Program first started
- 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
- 4<sup>th</sup> edition of the Sjögren's Syndrome Handbook written and printed

## 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 hearing.
- New research showed that it takes an average of 4.7 years to diagnose Sjögren's

## 2013

- SSF begins partnership with the LAM Clinics to create "Sjögren's Pulmonary Clinics"
- First Set of Sjögren's Clinical Practice Guidelines draft published by the SSF Medical & Scientific Advisory Board
- 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 Carroll Petrie Foundation Sjögren's Awareness Ambassador Program


**in memoriam**
**In Memory of Carol Ann Simpson**

Debbie Simpson  
Gloria Simpson

**In Memory of Arthur Rudolph**

Elaine & Larry Levin

**In Memory of****Constance "Connie" Larson**

Darryl & Nicole Butterfass  
Sherri, Leslie & Gaylene Barnes  
Lakes in Duluth  
The Ployhar Family  
Mental Health Systems, PC  
Diane Eldredge  
Dawnn Willette  
Lisa Leet

**In Memory of David Baker**

James & Dannielle Wascom

**In Memory of David Strick**

Elaine & Larry Levin

**In Memory of Florence Howie**

Linda & Frank Iannucci

**In Memory of Jane Patricia Ross**

Jane Ross

**In Memory of Jo Ludwig**

Paul Singley  
Tricia Daugherty  
Jim & Eileen Flanagan  
ORNL's Nuclear Science  
& Engineering Directorate

**In Memory of Lawrence Taylor**

Lynne & Lance Forstot  
Bobette Morgan

**In Memory of Robert Kenney**

The Greenstreet Family  
Gary & Linda Moss

James & Barbara Kenney

Kevin & Michele Kissling

Vincent & Catherine Piscitelli

R. Lipinski

Clare McGrail

Robert & Elizabeth Gordon

Ann & Jim Lonaberger

Charles & Kathy Foell

Faith & David Rose

Ethel Ann & Michael Brown

Linda & Ira Hoffman

All of Robert's Pool Volleyball Buddies

Anna May & Bob Austin

John & Marilyn Ginley

Sylvia & Meyer Silverman

Theodore & Denise Demarino

Patricia & James Stabilito

Rosemarie & Ken Arnold

Vic & Linda Rieder

Steve & Mary Wouch

Jim & Doreen Conway

Michelle Pedersen

Joseph Corcoran

Walter Granville

**In Memory of Geraldine Lauria**

Robert Lambert

**In Memory of****Sara Jane Pflieger Evans**

Berwick YMCA,  
5pm H2O Aerobics Class

**In Memory of Sue Henriksen**

Craig & Sue Moorhead  
Linda Wright

Don & Sharon Warbington

William & Marilyn Durand

Louise Frazier

Martin Biscorner

Wendy Wickert

Suzie Dietz

Rebecca Schechter

Bob Dunn and Robin & Janet

Sue Fortescue

John & Sandra McClure

Richard & Jane Christy

Karen Morgante

Alice & Tom Streeter

Lorie Monusko and Family

Jill & Dave Miner

Gary & Herb Brown

Dale & Pat Brandes

Don & Marian Olsen

Lynn Henriksen

Carolyn & Jeffrey Volk

Michele Strojek

Marjorie Frazier

Laurie Tallio

Lynne Elsesser

**In Memory of Helen Crosland**

Pete & Debbie Vaky

Susan & Gary Sperduto

**In Memory of Syble Stinson**

Deborah Stone

**In Memory of Nolena Elliott**

Hal & Cindy Gibson and  
Katie & Crystal

**In Memory of Nicholas Holler**

Margaret Holler

**In Memory of Kathy Parsons**

Dick & Lori Gaulke

**In Memory of JoAnne Markosky**

Carol & Tia Ekonomides

**In Memory of Connie Rodriguez**

Camille M. Bertram

Helen & Tom Wilson

N.C. Natividad

Seckyue Fulbeck

Mr. & Mrs. Ronald Foster

**In Memory of****Debra Ann Ballard Slater**

Amanda Jarnagin

**In Memory of Albert Ciacchio**

Albert & Lauren Lindsey

**In Memory of Ruth Kemper**

Ava Lee

Joyce Klemke

Bealeton/Remington Senior Center

Ralph Thwaite

Jim & Mary Anne Templeton

**In Memory of Patricia Ward**

Jeffrey & Lori Long

Edgar & Rose Wright

**In Memory of Louila Kaneaster**

Van & Marilyn Moore


**in honor**
**In Honor of World Sjögren's Day and our 21<sup>st</sup> Wedding Anniversary**

Bobbie & Ronald Bajda

**In Honor of Dr. Carkin for being a talented MD**

Misty Nordale

**In Honor of Lisa Yena**

Dr. John & Donna Yena

**In Honor of Elaine & Herb Harris' 65th Wedding Anniversary**

Gail & Jerry Ellstein

**In Honor of Bobby & Mort Weisenfeld's Birthdays and Anniversary**

Bert Cohen

**In Honor of Dr. S. Lance Forstot**

Dr. Udell

**In Honor of Maria Metropulos' Bridal Shower**

Effie Stevens

**In Honor of Kristie Rhodes' 40th Birthday**

Aunt Toni & Uncle Jimmy

**In Honor of Jacqueline Richmond,  
JVR Communications' Commitment to the Foundation**  
Emily Brown, White House, LLC



## Join Team Sjögren's as they heads to the most magical race on earth!

**T**eam Sjögren's is hitting the road again and heading to The Walt Disney World® Marathon & Half-Marathon on January 11-12, 2014!

Instead of starting your New Year with a resolution, start it by walking or running in the upcoming Team Sjögren's Marathon & Half-Marathon at Disney. Sign up for this experience of a lifetime, while also raising awareness and vital funds for education and research of Sjögren's. If you're unable to run or walk in a marathon, consider recruiting someone you know to run or walk in your honor.

The Walt Disney World Marathon and Half Marathon course takes you through all four Walt Disney World Theme Parks. Starting at Epcot, you will continue on to the Magic Kingdom Park, Disney's Animal Kingdom Park and Disney's Hollywood Studios before a picture worthy finish back at Epcot, where you'll receive your all new Mickey Mouse finisher medal!

As a member of Team Sjögren's, you will receive world-class training along with mentorship from past runners and Foundation Staff. Our team trainer and

nutritionist will be there to help guide you and ensure you're ready to complete the 13.1 or 26.2 miles.

Due to the popularity of The Walt Disney World® Marathon & Half-Marathon, we have limited spaces available. For more information about training and fundraising requirements, please contact Steve Taylor at 800-475-6473 or [staylor@sjogrens.org](mailto:staylor@sjogrens.org).

Just imagine how you will feel when you cross that finish line at the most magical place on earth!



# Help Us Celebrate 30 Years and Ensure 30 More!

Since 1983, the Sjögren's Syndrome Foundation's mission has been consistent:

- Educate patients and their families about Sjögren's.
- Increase public and professional awareness of Sjögren's.
- Encourage research into new treatments and a cure.



Thanks to the support of donors like you and countless committed volunteers, we remain the only national non-profit organization dedicated to conquering Sjögren's. In addition to providing patients with practical information and coping strategies, the Foundation is the clearinghouse for medical information and recognized as a national advocate.

Over the past 30 years it's been your ideas, suggestions and comments that have helped to shape our organization. The SSF staff, along with our dedicated Board of Directors, comprised of patients, healthcare professionals and interested individuals, work to ensure that all Sjögren's patients are given the quality care needed.

With the launch of our recent *5-Year Breakthrough Goal*, the Foundation continues to be an industry leader, bring together worldwide researchers, organizations, and pharmaceutical companies interested in developing new therapies.

The Foundation is only able to grow with the generous and continued support you have given. When looking at how far the Foundation has come in the past 30 years and how many people we have been able to help, just imagine what we can accomplish in 30 more!

Help us celebrate our accomplishments and continue on our journey of conquering Sjögren's by donating in honor of our 30th Anniversary below.

Please complete the following:

\$30     \$100     \$250     \$500     \$1,000     Other \_\_\_\_\_

Mail to SSF, BB&T Bank · PO Box 890612 · Charlotte, NC 28289-0612 or Fax to: 301-530-4415

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Telephone \_\_\_\_\_ E-Mail \_\_\_\_\_

Enclosed is a check or money order (in U.S. funds only, drawn on a U.S. bank, net of all bank charges) payable to SSF.

MasterCard     VISA     Discover     AmEx    Card Number \_\_\_\_\_ Exp. Date \_\_\_\_\_

Signature \_\_\_\_\_ CC Security Code \_\_\_\_\_

# September

## Breakthrough Bullet:

"When you're so tired it's hard to explain but the quality of your life goes down. I'd go to the doctor and say 'I don't feel good' and they didn't know why. I am thankful I finally have a diagnosis and am now focused on getting better."

*Venus Williams, Professional Tennis Player*

50%  
in 5 years  
Sjögren's  
syndrome  
FOUNDATION

When the Sjögren's Syndrome Foundation was first started by Elaine Harris, board meetings were held in her living room and a cup for donations was passed around at meetings to raise funds for office supplies such as stationary and postage. While the Foundation has always been a patient focused organization, it has grown from a "Mom & Pop" operation that was started 30 years ago to an internationally recognized organization shaping the industry in terms of research, education, patient care, advocacy and new therapies.

With the launch of the Foundation's largest awareness initiative in history, our *5-Year Breakthrough Goal*, we continue to lead the industry on behalf of all patients who suffer from this debilitating disease. We believe that reaching our Goal will benefit all patients because as physicians start to see Sjögren's more in their practice, they will need to become more knowledgeable about the different manifestations of the disease and treatment options.

While reading this issue of *The Moisture Seekers*, look for opportunities where you can add your voice to ours. Help us create a future where it takes half the time to be diagnosed, and where Sjögren's is taken more seriously by the medical community.

Together, we can make a difference! Here are just a few reasons why achieving our Goal is so important:

### Seen and heard around the SSF:

"I was diagnosed, FINALLY, after more than 20 years of seeing doctor after doctor. Just the peace of mind knowing that something was truly wrong has helped me cope so much better." – Dorla

"I was diagnosed in 2008 with Sjögren's, but I'm doing better today with all the help, support and just knowing I'm not alone!" – Jan

"The information you [the SSF] provide is priceless. I appreciate you guys immensely!" – Tati

"It will take an army to achieve our goal, but just imagine if we all band together – how we could change the face of Sjögren's for all patients, present and future!" – Steve Taylor, SSF CEO ■



**Elaine Harris**  
 Founder, First President, First Executive  
 Director, and Newsletter Editor for 10 years

### Past and Present Leadership

<i>Elaine Harris</i>	<i>President</i>	<i>1983 – 1991</i>
<i>Ann Imperio</i>	<i>President</i>	<i>1991 – 1992</i>
<i>Jean Kahan</i>	<i>President</i>	<i>1992 – 1996</i>
<i>Katherine M. Hammitt</i>	<i>President</i>	<i>1996 – 2000</i>
<i>Arthur Grayzel, MD, FACR</i>	<i>President</i>	<i>2000 – 2002</i>
<i>Ann Race</i>	<i>President</i>	<i>2002 – 2004</i>
<i>Philip C. Fox, DDS</i>	<i>President</i>	<i>2004 – 2006</i>
<i>Bobette Morgan</i>	<i>Chairman</i>	<i>2006 – 2008</i>
<i>Gary Foulks, MD, FACS</i>	<i>Chairman</i>	<i>2008 – 2010</i>
<i>Lynn M. Petruzzi, RN, MSN</i>	<i>Chairman</i>	<i>2010 – 2012</i>
<i>S. Lance Forstot, MD</i>	<i>Chairman</i>	<i>2012 – current</i>

30  
 Years

## Leave Behind a Legacy of Hope for the Future!

Elaine Harris is a shining example of how one person can make a big difference. It's this philosophy that has been the base of the Sjögren's Syndrome Foundation's success, which is why we consistently call on members and friends to "Step Up for Sjögren's" in various ways.

By recognizing the SSF in your will or leaving us your estate, you will be leaving your own legacy by ensuring that advancements of innovative research, patient support and physician education programs continue at the SSF.

We encourage you to talk to your estate planner about planned giving and how you and your loved ones can best benefit from your generosity.

### Three ways you can include the SSF in your will:

- A specific bequest is the most common. You leave a specific amount of money, a specific asset, or a specific percentage of your estate to SSF.
- A residual bequest benefits the SSF only after all debts, expenses, taxes, and other bequests have been paid from your estate.
- A contingent bequest only benefits the SSF if other beneficiaries cannot accept it. For example, "If my husband should predecease me, then I leave my entire estate to the Sjögren's Syndrome Foundation for the benefit of the unrestricted endowment fund."

For more information about including the SSF in your will and giving us a future filled with hope, please contact Ben Basloe at 800-475-6473 x207 or [bbasloe@sjogrens.org](mailto:bbasloe@sjogrens.org).

Sjögren's Syndrome Foundation  
*Legacy of Hope*

# A Special Thank You

... to all of the companies and organizations that participated in the 2013 "Bold Blue Day" initiative, increasing Sjögren's awareness while helping to raise crucial funds for life-changing research by hosting a dress-down blue jeans day in honor of Sjögren's!

Acosta's Stone Work  
 Advocate Health Care  
 AW Becker Elementary School  
 Bayer Healthcare LLC  
 B-E Accounting & Tax P.C.  
 Belcan Corporation  
 Blue Ridge Health Center  
 Bogey Hills Vision Center  
 Bonner Eye Clinic  
 Boulder Creek Golf and Country Club  
 Catholic Health Association  
 Central Credit Union of Florida  
 CIGNA  
 City Court of Houma  
 Department of Public Advocacy, State of Kentucky  
 Doctor my Eyes  
 Doris Mackins & Friends  
 Dreher High School  
 East Kingston Elementary School  
 Eyetopia Eyecare  
 Family Dental Center  
 Franklin County Sheriffs Dept.  
 gloprofessional  
 Innate Concepts Chiropractic  
 International Autoimmune Arthritis Movement (IAAM)  
 Isabella Bank  
 Kernersville Chamber of Commerce

Leaders Heights Elementary School  
 Life Care Center of Morehead  
 Littler Mendelson P.C  
 Loganville-Springfield Elementary School  
 Mavenspire, Inc  
 Mount Prospect Child Care Center Inc.  
 Nancy Sarow- Saint John Vianrey Womens Scripture Group  
 Naval Chaplaincy School and Center  
 OCuSOFT, Inc.  
 Old Republic Title  
 Ole' Hickory Classic  
 Prairie Point Elementary  
 PRN-Physician Recommended Nutriceuticals  
 Professional Eye Care Associates of America  
 Pyramid Counseling Services  
 Simply Measured  
 Skadden, Arps, Slate, Meagher & Flom LLP  
 SmartCrowdz  
 University of Albany, SUNY  
 University of Minnesota School of Dentistry  
 Victor Porter Agency, P.C  
 Vital Signs  
 Westin Lake Las Vegas  
 Yanni's Restaurant

Ask your school / company **TODAY** about going **Bold Blue for Sjögren's Awareness this year!**

To learn more about hosting a "Bold Blue Day," contact Steph Hilton at  
 (800) 475-6473 ext. 227

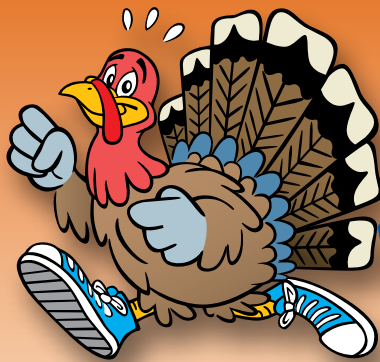
## *The Moisture Seekers*

Sjögren's Syndrome Foundation Inc.  
6707 Democracy Blvd., Ste 325  
Bethesda, MD 20817

Phone: 800-475-6473

Fax: 301-530-4415

*If you would like to receive this newsletter but are not currently an SSF Member, please contact us! 800-475-6473*



# Team Sjögren's

We hope this Thanksgiving you will consider participating in your community Turkey Trot as member of Team Sjögren's!

What a great way to start your day of giving thanks - by purchasing a Team Sjögren's Turkey Trot Kit and walking or running with others in your area, increasing awareness for Sjögren's and helping raise crucial funds for Sjögren's research.

### *Your Kit Includes:*

- Awareness Bracelet
- Team Sjögren's T-shirt
- Certificate of Participation
- "What is Sjögren's Syndrome?" Brochures

### *Find Your Local Turkey Trot:*

You can find a local Turkey Trot by visiting [www.active.com](http://www.active.com). Then enter your state and type in "Turkey" under keyword search. You can also check with your local newspaper or search online.

If there's not a race near you, consider asking family and friends to join you for a morning walk on Thanksgiving in your neighborhood while wearing your Team Sjögren's T-shirts!

*Price: \$30 plus shipping and handling*

Order your Team Sjögren's Goes Turkey Kit today by calling 800-475-6473 or online by visiting [www.sjogrens.org](http://www.sjogrens.org).

