You are invited to attend the

Connecticut Chapter
Sjögren’s Syndrome Support Group Meeting

Sunday, May 20th, 2012

1:30 p.m.

“Round Robin”, a “Sharing and Caring” discussion of Sjögren's Syndrome with Kathy Heimann, discussion leader. This is a chance to ask questions and talk to others who have Sjögren's Syndrome.

Meeting Location:
UConn Health Center, Farmington, CT
Onyiuke Faculty Dining Room

**Directions:** I-84 to Exit 39. Take a right onto Farmington Ave. Continue following signs to the UConn Health Center. Follow the blue “H” (Hospital) signs to the flag poles at the top of the hill. Park in “Visitor” Parking. Once inside the building, follow the signs to the Cafeteria. The meeting is in the Onyiuke Faculty Dining Room at the left rear of the cafeteria.

*Free samples, literature, and refreshments are always available. Family and friends are welcome.*

---

**Connecticut Chapter**

**Officers**
- Mary Beth Walter, President, 860-569-6933
- Ken Walter, Vice-President, 860-906-4851
- Susan Meyer, Secretary, 860-651-4485
- Cliff McKibbin, Treasurer, 860-673-1584

**Medical Advisors**
- Ann Parke, MD
- Dimitri Perdikis, DDS

**Volunteer Committee**
- Fred Heimann, Kathy Heimann, Ilene Kaplan, Lucille McKibbin, Tina Moskwa, Marilyn Sousa, Rachel Yardeni, Susan Zimmerman
“New Concepts about Sjogren’s Syndrome and its Treatment”

The March meeting featured a talk by our Medical Advisor, Dr. Ann Parke, Rheumatologist, Professor of Medicine, University of Connecticut Health Center at St. Francis Hospital and Medical Center. The current definition of primary SS includes a triad of complaints: Keratoconjunctivitis Sicca (dry eyes); Xerostomia (dry mouth); and a connective tissue disease. Secondary SS can occur with any of the connective tissue diseases: Systemic Lupus Erythematosus (SLE), Limited Scleroderma (CREST), or Rheumatoid arthritis (RA). It has been estimated that 50% of RA patients have SS.

Some of the current concepts regarding SS include: 1) It is the most common autoimmune disease; 2) It is a lymphocyte aggressive disease in that the lymphocytes invade the glands. While SS patients have an increased risk of lymphoma (usually B cell lymphoma), which occurs in less than 10% of patients, it is often a low grade lymphoma and patients generally do well. Dr. Parke is now less concerned with lymphoma and many other researchers now believe that lymphoma does not necessarily alter lifespan for Sjogrens patients.

Another current concept is that SS is a systemic autoimmune disease that preferentially attacks the exocrine glands and that we should be more aggressive in managing the disease. The latest terminology is “autoimmune exocrinopathy”.

One of the new concepts is that SS may be an SLE of the mucus membranes. She cautioned us to not be alarmed by this terminology in that all SLE is not serious. SLE is a systemic disease associated with the production of non organ specific auto-antibodies, classically antinuclear anti-bodies (ANA). The auto-antibodies, Ro and La, are associated with SS, neonatal lupus syndrome, and the photosensitivity experienced by SLE patients. We still lack a reproducible marker for SS.

HIV and chronic hepatitis C produce pathology similar to SS but point to the idea that SS may be triggered by a virus. SLE patients have a 40 fold (4000%) increase in Epstein Barr viral load compared to controls.

The current treatment of SS includes the use of the anti-malarial drug Hydroxychloroquine (Plaquenil) which is also the cornerstone of Lupus therapy. This drug helps with fatigue and joint pain. The biologics Enbrel, Remicaid, Humira, Cinzia, and Simponi have revolutionized the treatment of RA, but include risks of serious infections, can reactivate old TB, and can promote the development of lupus-like disease and do not appear to be of benefit for patients with Sjogrens Syndrome.

Susan Zimmerman and Tina Moskwa have joined Team Sjogren's participating in the 2012 Country Music Marathon in Nashville on April 28th. Team Sjogren's is a group of patients and family members from around the country who have been sponsored to participate. The goal is to raise funds for research and education about Sjogren's Syndrome.