In response to patient concerns about medical care and physician inquiries regarding therapeutic dilemmas, the Sjögren’s Syndrome Foundation launched an initiative several years ago to develop Clinical Practice Guidelines for the disease. Working groups were formed to concentrate on three major areas including Rheumatologic/systemic manifestations, Ocular and Oral problems. These guidelines are now well underway, and recommendations for initial clinical questions are either about to be published, in the final stages of consensus or being drafted. “This initiative marks one of the biggest undertakings that the Foundation has ever made! Recognizing the critical need for Clinical Practice Guidelines to improve care for Sjögren’s patients and provide consistent, evidence- and/or expert-based guidance to healthcare providers, the SSF Board of Directors was determined to make this initiative a Foundation priority,” says Steven Taylor, SSF CEO.

Continued on page 2
This project is being conducted with the guidance and assistance of the Quality of Care Committee and staff of the American College of Rheumatology (ACR) but under the auspices of the Sjögren’s Syndrome Foundation. Amy Miller as lead staff for this ACR committee has been especially helpful. The initial guidelines will focus on Sjögren’s patients in the United States and address U.S.-specific healthcare products, systems and insurance company requirements. In addition to the extraordinary commitment of SSF staff – especially lead staff Katherine Hammitt, MA – and other Foundation resources to this project, nearly 50 volunteers are serving on the three Working Groups to draft recommendations. Additionally, more than 50 volunteers also are contributing to the guidelines as Consensus Panel members.

While specialists in rheumatology, ophthalmology, optometry and oral medicine form the majority of volunteers, representatives from other backgrounds and specialties are involved in specific topics and in the consensus process. These include patients, nurses, neurologists, neuropsychologists, psychiatrists and oncologists. The SSF is grateful to the professional leaders of this initiative (see list of leaders and participants on page 6), including Guidelines Chair, Frederick B. Vivino, MD, MS, the American Dental Association (ADA) for contributing staff time and expertise in guidelines development and literature searches for the oral aspects of the Guidelines, the University of Pennsylvania librarian, Rebecca Landau, who helped with other literature searches, and methodology expert and Sjögren’s patient Patricia Hurley, MSc who helped par-

Key Topics and Clinical Questions

Goals for Guidelines Development

The overall goals for the development of the SSF Clinical Practice Guidelines were delineated as follows:

1. Improve quality and consistency of care for patients with Sjögren’s syndrome by developing Clinical Practice Guidelines for the assessment and management of the systemic manifestations, dry eyes, and dry mouth.

2. Create a document (including an on-line electronic version) delineating Clinical Practice Guidelines in Sjögsen’s for U.S. clinicians.

3. Obtain broad acceptance of the guidelines by key professional and government organizations.

Methodology

Guidelines members developed and followed a highly rigorous process for developing the SSF Clinical Practice Guidelines based on ACR quality of care standards.

Transparency as a Priority

Transparency and full disclosure were deemed paramount to the process of the Clinical Practice Guidelines development. Meticulous minutes and other notes have been maintained to document the process fully and are being and will be used to elucidate all processes and decisions. Oversight is maintained by the Guidelines Chair and Working Group Chairs. Strict conflict of interest protocols are in place, and all guidelines participants have completed and maintained ACR conflict of interest forms. The conflict of interest among guidelines members currently stands at 36%; the ACR limit on conflict of interest is 49%.

The Process

Literature searches were conducted in standardized fashion by all Topic Review Groups (TRGs) to address specific clinical questions. Publication dates and language, study types (e.g. meta analyses, randomized controlled trials, etc.) and databases to be searched were determined. Guidelines Protocol Worksheets were designed and completed to clearly define systematic review parameters and definitions to be used in study evidence
and quality assessment tables. A minimum of two people reviewed the literature, selected relevant studies and extracted the data. Data extraction tables were designed to include information on 1) Study Characteristics; 2) Sample and Disease Characteristics; 3) Evidence (including outcome measures); and 4) Study Quality. The Rheumatology/Systemic Working Group set March 31, 2013 as the end date for publications included for consideration in the development of its first set of recommendations. Common end dates for all additional Topic Review Groups will be updated as necessary.

The strength of evidence data was determined using a modification of GRADE methodology. Various guidelines experts from multiple professional societies including the founder of the GRADE evidence-based system were continually consulted on an as-needed basis. Note that a “Statement Regarding Decision on Grading the Quality of Evidence” was drafted by guidelines members and can be seen on page 7.

Initial recommendations were then drafted by the TRG and Working Group Chairs. A consensus Delphi-type process has been developed for all Working Groups to follow in order to obtain agreement on draft recommendations and ensure lack of bias. Consensus Panels were formed and are in the process of being formed. Ultimately, ≥75% agreement is required; if this level of agreement is not reached, this will be stated. Consensus panelists include community and academic specialists whose experience is relevant to a specific set of clinical questions as well as other key stakeholders such as patients.

Consensus Panels receive literature search data with summary/background information, including Evidence Tables. To gauge the level of agreement, a 6-point Likert Scale is utilized. To help with revisions of draft recommendations, panelist comments are encouraged. Multiple rounds of voting may take place, with recommendations continually revised according to panel responses until final recommendations are approved. Consensus Panel responses are anonymous. Consensus Panels are made up of 30-40 members for each Topic. Panel composition changes slightly depending on the content expertise needed for each guideline question and availability of panelists.

Co-Chaired by Steven E. Carsons, MD and Ann Parke, MD, the Rheumatology/Systemic Working Group identified 97 ideas for topics on the first pass! Following a thorough discussion of these topics and the survey results, members voted and ranked the topics, narrowing them to 16 key areas. (See Table 1.) Final topics were ranked from 1-5 by the Rheumatology Working Group by email vote. Nine topics received a mean score of >4.0 and were selected for initial guideline development.

Topic Review Groups (TRGs) were assigned to address each area for the first two rounds of recommendations. The groups started by posing clinical questions in a PICO (Population, Intervention, Comparison and Outcomes)-type format. Round One Topics were selected on the basis of feasibility as well as rankings and include:

- The effectiveness and use of biologics for inflammatory musculoskeletal pain
- Management of fatigue

### Table 1

**Top Areas of Coverage for Rheumatological/Systemic Aspects of Sjögren’s**

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1.</td>
<td>How to screen for lymphoma in primary SS?</td>
</tr>
<tr>
<td>2.</td>
<td>How should neuropathic pain be managed in SS (immunomodulatory and non-immunomodulatory therapies)?</td>
</tr>
<tr>
<td>3.</td>
<td>How to evaluate SS patients with persistent fatigue?</td>
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<tr>
<td>4.</td>
<td>Which treatments help inflammatory arthralgias, myalgias, and arthritis in SS?</td>
</tr>
<tr>
<td>5.</td>
<td>Are biologic and oral DMARDS effective for the sicca component of SS?</td>
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<tr>
<td>6.</td>
<td>Which biologics could be considered for treatment of SS?</td>
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<tr>
<td>7.</td>
<td>How should fatigue be treated in primary SS?</td>
</tr>
<tr>
<td>8.</td>
<td>What is the scope and how do you treat CNS involvement in primary SS?</td>
</tr>
<tr>
<td>9.</td>
<td>How should SS-related cutaneous Vasculitis be managed in SS?</td>
</tr>
<tr>
<td>10.</td>
<td>Is B cell depletion beneficial for treatment of primary SS?</td>
</tr>
<tr>
<td>11.</td>
<td>How to monitor for pulmonary disease in SS?</td>
</tr>
<tr>
<td>12.</td>
<td>Which vaccines are recommended for SS patients?</td>
</tr>
<tr>
<td>13.</td>
<td>Is CV risk elevated in primary SS and how to screen?</td>
</tr>
<tr>
<td>14.</td>
<td>Should patients with pulmonary disease be managed aggressively early in their disease?</td>
</tr>
<tr>
<td>15.</td>
<td>Should a Sjögren’s QOL/impact assessment be validated for U.S. patients and be recommended for management of SS?</td>
</tr>
<tr>
<td>16.</td>
<td>Should primary SS patients be screened for renal disease?</td>
</tr>
</tbody>
</table>

*Note: In ranked order of preference for coverage*
Specific clinical questions to be addressed by recommendations during the first round can be viewed in Tables 2, 3 and 4. Round Two Topics include CNS and Cognitive Dysfunction; Peripheral Nervous System Involvement; and Lymphoma.

Dr. Carson is Chief, Division of Rheumatology, Allergy and Immunology, Winthrop University Hospital, and Professor of Medicine, SUNY, Stony Brook, Mineola, New York; Dr. Parke is a Professor of Medicine, University of Connecticut Health Center at St. Francis Hospital, Hartford, Connecticut.

Oral Manifestations

The Oral Working Group is co-chaired by Troy E. Daniels, DDS, MS, Professor of Oral Medicine and Pathology, Schools of Dentistry and Medicine, University of California, San Francisco and Michael Brennan, DDS, MHS, Oral Medicine Residency Director, and Director, Sjögren’s Syndrome and Salivary Disorders Center, Department of Oral Medicine, Carolinas Medical Center, Charlotte, North Carolina. This group identified three key topic areas and ranked them in the following order:

- Caries Prevention
- Caries Management and Restoration
- Mucosal Management and Symptom Relief

For Round One/ Caries Prevention, four sub-topics were designated and Topic Review Groups formed to develop recommendations for each:

- Fluoride
- Salivary stimulation/enhancement
- Antimicrobial agents
- Non-fluoride remineralizing agents

See Table 5 for the Clinical PICO Questions that currently are being addressed.
Table 5
Oral Manifestations – Round One Clinical Questions

The Use of Fluoride for Caries Prevention in Primary Sjögren’s Patients:

1. In primary Sjögren’s patients, does the use of a topical fluoride compared to no topical fluoride reduce the incidence, arrest or reverse coronal or root caries?

2. In primary Sjögren’s patients, is one topical fluoride agent more effective than another in reducing the incidence, or to arrest or reverse coronal or root caries?

The Use of Salivary Stimulants in Caries Prevention in Primary Sjögren’s Patients:

1. In primary Sjögren’s patients, does salivary stimulation compared to not stimulating saliva flow reduce the incidence, arrest or reverse coronal or root caries?

The Use of Antimicrobial Agents in Caries Prevention in Primary Sjögren’s Patients:

1. In primary Sjögren’s patients, does the use of antimicrobial agents compared to placebo reduce the incidence, arrest or reverse coronal or root caries?

The Use of Non-Fluoride Remineralizing Agents in Caries Prevention in Primary Sjögren’s Patients:

1. In primary Sjögren’s patients, does the use of non-fluoride remineralization agents compared to placebo reduce the incidence, arrest or reverse coronal or root caries?

2. In primary Sjögren’s patients, does the use of non-fluoride remineralization agents compared to the use of fluoride reduce the incidence, arrest or reverse coronal or root caries?

Table 6
Ocular Management – Clinical Topics

Evaluation of Dry Eye Disease (DED)

A. Symptoms
B. Objective signs

General Management

A. Control of the environment
B. Lifestyle changes
C. Lid hygiene
D. Nutritional support

Therapeutic Treatment

A. Topical tear substitutes and lubrication
B. Anti-inflammatory therapy (corticosteroids, topical cyclosporine, Omega 3 essential fatty acids)
C. Secretagogues
D. Punctal occlusion (temporary and permanent)
E. Autologous serum
F. Mucolytic therapy
G. Therapeutic contact lenses
H. Eyelid surgery

Treatment and Management of Meibomian Gland Dysfunction

Co-Chairs of the Ocular Working Group are Gary Foulks, MD, Professor Emeritus and Former Director, Cornea Service, Kentucky Lions Eye Center, Department of Ophthalmology and Visual Sciences, University of Louisville, Louisville, Kentucky and S. Lance Forstot, MD, Clinical Professor of Ophthalmology, University of Colorado School of Medicine, Denver, Colorado. The Ocular Working Group has been able to forge ahead more quickly than other areas because of the success and subsequent 2007 publication of the International Dry Eye Workshop (DEWS), sponsored by the Tear Film & Ocular Surface Society. The DEWS initiative was launched to address the critical need for definition, classification, epidemiology, diagnostics, management strategies, therapeutics and clinical trial design in Dry Eye Disease (DED). The SSF Ocular Working Group built on the DEWS initiative and narrowed the SSF Guidelines to focus on Sjögren’s-specific DED.

SSF Guidelines for Ocular Management are based on the nature of the dry eye and severity of symptoms. Members lead with an explanation of the definition and classification of DED and a clinical perspective on keratoconjunctivitis sicca (KCS) associated with Sjögren’s-specific dry eye compared to dry eye from other causes. Dry eye in Sjögren’s can be classified as aqueous-deficient dry eye (ADDE) in which tear production is reduced and evaporative dry eye (EDE) in which the evaporation of the tear film is abnormally high, although both frequently occur together in the Sjögren’s patient. Management of meibomian gland dysfunction also is included as a frequent co-morbid condition in the Sjögren’s DED patient. Key areas of coverage are delineated in Table 6.

To further help guide the healthcare professional, a treatment algorithm was devised. Publications were graded according to the American Academy of Ophthalmology Preferred Practice Pattern guidelines in addition to the GRADE system used by the Rheumatology/Systemic and Oral Working Groups.
Challenges

Guidelines participants have faced numerous challenges in the development of Clinical Practice Guidelines for Sjögren’s. First, the comparability of published study populations presented an obstacle, because different classification and/or diagnostic criteria have been used through the years to define Sjögren’s syndrome. Guidelines members decided that any of the previously published criteria would be deemed acceptable.

Second, many different methods are utilized in the Sjögren’s literature to assess a particular outcome. Each Topic Review Group discussed and arrived at a consensus regarding the outcome measures to be used by reviewers of the literature in advance of selecting studies for inclusion in order to reduce potential bias. Generally, these measures were selected according to frequency of use in clinical trials and availability in clinical practice. An additional challenge was that clinical trials often report multiple subspecialty-specific outcomes, for example, the effect of a therapeutic agent on dry eye, salivary flow and joint pain. As a result, the same study was or will be reviewed more than once for subspecialty content by different Topic Review Groups.

Finally, as all clinicians know, a limited body of evidence is available from the Sjögren’s literature upon which to base clinical decisions. When evidence is scanty or not available, expert opinion is tapped for drafting recommendations. Regardless of the strength of the published evidence, a Delphi-type process employing a broad-based consensus panel has been created to approve and finalize recommendations.

Final Comments

Despite the time and resources required to complete this enormous undertaking, all participants are firmly committed to help the SSF meet its goals. It is hoped that the Clinical Practice Guidelines will dramatically improve standards and consistency of care in the United States within the next ten years. The SSF also hopes that recommendations will increase awareness and education about Sjögren’s and help guide insurance reimbursement policies.

As this article goes to press, the first set of recommendations is undergoing the Consensus Panel process. As recommendations are developed, Guidelines members plan to report on final recommendations at professional meetings, publish in journals representing their respective specialties, and, in the end, compile all recommendations into one publication. Gaps in scientific knowledge will be identified as areas of future study so that unproven treatments and methods of management can be further assessed. Guidelines members recognize that recommendations are a work in progress and will need continual updating as new studies are published. In the future, the Clinical Practice Guidelines committee also hopes to engage colleagues in Europe and Asia for further guidelines development with a more global perspective.
SSF Clinical Practice Guidelines  
Statement Regarding Decision on Grading the Quality of Evidence

The members of the SSF Clinical Practice Guidelines Committee felt it was important to formally appraise the quality and strength of evidence that would inform the guideline recommendations. The Committee gave extensive and thoughtful consideration to the many approaches available for determining the quality of evidence for the clinical practice guidelines. The Committee focused on ensuring that the selected methodology would: facilitate the critical appraisal of the evidence; establish the quality of the evidence, including an indication of the extent of its risk of bias; be rigorous and reliable; help to ensure transparency; and take the limited resources of the SSF and the Committee into consideration.

Committee members concluded that a simplified system that would take advantage of elements from systems and programs held in high regard would be best suited for the SSF guidelines. The system chosen was primarily adapted from methodology used by GRADE and AHRQ. There were three key steps to the appraisal identified by the Committee: 1) a transparent appraisal of the quality of the individual sources (i.e., any individual trials, systematic reviews, etc.) using pre-specified criteria, based primarily on elements of quality related to study design, methodology, and risk of bias; 2) rating the strength of the total body of evidence to evaluate its overall risk of bias, and the overall validity and reliability of the total body of evidence; and 3) rating of the strength of the recommendations.

2013 SSF Student Fellowships Awarded

Each year the SSF partners with three outstanding organizations to offer student fellowships in Sjögren’s. Our partners include the American College of Rheumatology Research Education Foundation (ACR REF), the American Association for Dental Research (AADR) and the Contact Lens Association of Ophthalmologists Education and Research Foundation (CLAO ERF).

These fellowships are possible through a generous grant from the Bannon Humphrey Foundation of Charleston, South Carolina. Thanks to their support, we are able to increase visibility and expand interest in Sjögren’s among future researchers and clinicians.

To help assist with selecting the recipients, the SSF appointed a Sjögren’s expert to each organization’s review team. We would like to give our sincere thanks to Vidya Sankar, DMD, MHS, Lance Forstot, MD and Philip Cohen, MD for volunteering their time and expertise to help choose the best applicants.

Award amounts are designated by the individual organizations and can be found on the presentation schedule. We will be recruiting candidates for next year’s awards beginning in the fall. If you know a student of high regard whom you feel would make a great candidate for these scholarships, we encourage you to discuss applying with them and mentoring them on their professional journey. This year’s awardees are:
He Li, PhD-Candidate at the Oklahoma Medical Research Foundation, Oklahoma City, Oklahoma. **Recipient of the CLAO-ERF fellowship** for study entitled: “Novel Biomarkers for Ocular Disease in Sjögren’s Syndrome.” The goal of the study is to utilize powerful genomic technologies to characterize the etiology of dry eyes and ocular surface disease in Sjögren’s and identify dysregulated genes in peripheral blood that potentially can be used as biomarkers for ocular involvement in Sjögren’s.

Adrienne Guana, PhD-Candidate in Oral Biology and Immunology and Microbiology at the University of Florida College of Dentistry, Gainesville, Florida. **Recipient of the AADR fellowship** for study entitled: “The Role of Differentially Expressed Co-Stimulatory Molecules on the T Cell Responses of Sjögren’s Syndrome.” The goal of the proposed research is to investigate the expression and functions of co-stimulatory molecules and their effects on T cells in primary Sjögren’s. Specifically, she plans to characterize the functions of CD80 and CD86 on T cell responses that contribute to disease initiation and progression, especially regarding regulatory T cell function.

Miguel-Angel Gutierrez, PhD-Candidate in Molecular, Cellular and Integrative Physiology at the University of California, Los Angeles, Los Angeles, California. **Recipient of the ACR Health Professional Preceptorship** for study entitled: “The Role of Dendritic Cells in the Initiation and Progression of Dry Eye in Sjögren’s.” Study aims to characterize dendritic cell (DC) subsets in the corneal epithelium and stroma, histopathology of cornea and lachrymal glands in MRL mice at different ages, immunohistochemistry for immune cells in cornea and lachrymal glands, as well as learn methods to manipulate DC subsets in vivo.

More information on SSF Student Fellowships and the SSF partnerships with professional organizations can be found at http://www.sjogrens.org/home/research-programs/student-fellowships.

**Did you know?**

Up to 40 percent of Sjögren’s patients will have neurological symptoms which antedate sicca manifestations.

Up to 50 percent of SS patients with painful neuropathies are not positive for SS-A or SS-B antibodies.

From Julius Birnbaum, MD, 2013 SSF National Patient Conference and based on the following publications as well as similar findings in the Johns Hopkins Sjögren’s cohort.


The SSF made appearances at both the AAOM conference in San Antonio in late April and the AOA conference in San Diego this June.

The AAOM conference had two presentations, “Sjögren’s Syndrome Update” presented by Troy Daniels, DDS, MS and “Management of Patients with Dry Mouth” presented by Vidya Sankar, DMD, MHS.

We thank Drs. Daniels and Sankar for their fantastic presentations as well as Michael Brennan, DDS, MHS for securing and planning for Sjögren’s to be presented at the conference. Nearly 300 attendees in all participated in the presentations and took home materials prepared by the SSF on Sjögren’s and the many resources that the SSF offers professionals.

The AOA’s Optometry Meeting in San Diego put an interesting spin on presenting Sjögren’s. “More than Meets the Eye - A Multidisciplinary Approach” was arranged by Robert Prouty, OD (Optometry) and presented by Nancy Carteron, MD (Rheumatology), Linda Nguyen, MD (Gastroenterology) and Vidya Sankar, DMD, MHS (Dental). This panel helped spread the word to the optometry community that Sjögren’s is more complex than dry eye alone and is a systemic disease for which optometrists can be the first line of defense to identify and make referrals to other professionals. Thank you to all the presenters for sharing their knowledge with the optometry community!
Clinical Trial in Sjögren’s
Seeking Participants

Participants are being sought for a new clinical trial sponsored by the National Institute of Allergy and Infectious Diseases (NIAID) for the treatment of primary Sjögren’s. The randomized, double-blind, placebo-controlled Phase 2 trial is evaluating the safety and efficacy of the therapeutic baminercept, a lymphotxin-beta receptor fusion protein made by Biogen Idec. For inclusion and exclusion criteria and full contact information on the nine centers in the U.S. at which trials are being conducted, search for Clinical Trials Identifier NCT01552681 at http://www.clinicaltrials.gov. Study chairs are E. William St. Clair, MD, Duke University and Judith James, MD, PhD, Oklahoma Medical Research Foundation.

Transitions...

Umesh Deshmukh, PhD has accepted a position as Associate Member in the Arthritis and Immunology Program at the Oklahoma Medical Research Foundation in Oklahoma City, Oklahoma. He joins Kathy Sivils, PhD, Director of the OMRF Sjögren’s Research Clinic, and Dr. Deshmukh is the recipient of the 2008 and 2009 SSF Innovative Concept Award for his project on “Adenosine receptor agonists: Novel therapeutic agents for Sjögren’s syndrome.” Dr. Deshmukh leaves the University of Virginia, where he was an Assistant Professor of Medicine in the Center for Immunity, Inflammation and Regenerative Medicine, Division of Rheumatology. He states “While I will continue my work to test novel therapeutic compounds and strategies to treat Sjögren’s syndrome, my move to OMRF will allow integration of human and mouse studies to better understand the disease pathogenesis.”

Andres Pinto, DMD, MPH, MSCE, FDS RC-SED has moved from University of Pennsylvania School of Dental Medicine to become the Chairman and an Associate Professor for the Department of Oral and Maxillofacial Medicine and Diagnostic Sciences at Case Western Reserve University’s School of Dental Medicine in Cleveland, Ohio. Dr. Pinto will retain his adjunct affiliation with the University of Pennsylvania. Dr. Pinto is a member of the SSF Medical and Scientific Advisory Board, and the SSF congratulates him on this move!

NIDCR Solicits Input on its Strategic Plan

The strategic planning process is under way for the National Institute of Dental and Craniofacial Research (NIDCR), the National Institutes of Health, and your input is needed! The strategic plan will guide NIDCR research priorities for the next six years (2014-2019). It is critical for all clinicians and researchers who have an interest in Sjögren’s to provide comments.

To provide input, please visit http://www.nidcr.nih.gov/NewsAndFeatures/Announcements/GiveUsYourIdea forNIDCRsNextStrategicPlan. The deadline has been extended and is coming up soon -- September 20, 2013.
**NIH Launches New Dietary Supplement Database**

The National Institutes of Health has launched a new database which will allow individuals to search the labels of dietary supplements. The Dietary Supplement Label Database (DSLD) is a joint project of the Office of Dietary Supplements (ODS) and the National Library of Medicine (NLM) of the National Institutes of Health (NIH).

The goals of the DSLD are to:

- Include the full label information from all of the dietary supplement products marketed in the U.S. with a Web-based user interface that provides ready access to the data;
- Serve the broader research community that has expressed the need for a DSLD;
- Serve as an educational and research tool for students, academics, other professionals, and potentially, health care providers and the public.

Considering the number of Sjögren’s patients who currently take dietary supplements to aid in the management of the disease, the DSLD could prove to be a very useful tool. An individual can search products, brands and ingredients. This can allow them to review the suggested use of a particular supplement, calories and daily values as well as search other brands and combinations that might be available. For instance, if a patient is taking fish oil and vitamin D, they could find a combination supplement rather than two separate supplements. This can result in easier maintenance of supplements and cost effectiveness for the patient.

You will find more information and search the DSLD at http://www.dsld.nlm.nih.gov.

Information in this article was found on the NIH DSLD webpage.

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Invaluable sources of information about Sjögren’s syndrome and the Foundation’s activities.

Co-authoring booklets, brochures, and a DVD may be helpful. Visit this site for resources available to other site visitors such as archives of the most popular newsletter, Regarded as the...
**Sessions on Sjögren’s!**

**Saturday, Oct. 26**

10:40 – 11:20am  
(The 2nd of 3 sessions scheduled from 10am-Noon)  
Pre-Meeting Course: Epigenetics of Autoimmune Disease – MicroRNA Expression Profiles in Sjögren’s Syndrome – Illias Alevizos, DMD, MMSc

**Monday, Oct. 28**

7:45 – 9:15am (033)  
Meet the Professor: Controversies in Sjögren’s Syndrome – Alan N. Baer, MD — Advance registration required

1:00 – 2:00pm  

Upon completion of this session, participants should be able to:  
- define key cytokine and death inducing pathways in systemic lupus erythematosus, myositis, rheumatoid arthritis and Sjögren’s  
- discuss what is known about tissue repair pathways in myositis and other rheumatic syndromes  
- review the impact of tissue damage and repair on our approach to the management of patients with rheumatic disease

6:30 - 7:45 pm  
ACR Study Group: Sjögren’s Syndrome – Jacques-Eric Gottenberg, MD, Moderator

**Tuesday, Oct. 29**

11am – Noon  
Oral Health in Rheumatologic Disease: What Every Rheumatology Practitioner Should Know About Oral Health and Diseases – Parish P. Sedghizadeh, DDS, MS  
Oral Health in Systemic Lupus Erythematosus and Sjögrens – Daniel Wallace, MD  
Oral Health and Osteoporosis Therapy – Stuart L. Silverman, MD

Upon completion of this session, participants should be able to:  
- recognize oral disease common to clinical practice of rheumatology  
- explain how to conduct a thorough oral examination and to identify oral anatomic structure  
- discuss the impact of Sjögren’s and systemic lupus erythematosus on oral health  
- describe the association of osteoporosis medications and osteonecrosis of the jaw

4:30pm – 6:00 (081)  
Meet the Professor: Controversies in Sjögren’s Syndrome – Alan N. Baer, MD — Advance registration required

**Wednesday, Oct. 30**

9:00-10:30am  
Current Management of Sjögren’s Syndrome  
Management of Dry Eye Disease in Sjögren’s Syndrome – George Papaliodis, MD  
Oral and Dental Care of the Patient with Sjögren’s Syndrome – Ava Wu, DDS  
Emerging Role of Biologic Agents in Sjögren’s Syndrome – E. William St. Clair, MD

Upon completion of this session, participants should be able to:  
- describe the management of patients with dry eye disease  
- summarize the proper oral and dental care for patients with Sjögren’s syndrome  
- outline the emerging role of biologic agents in the therapy of Sjögren’s syndrome

**Coming to ACR?**

Visit the SSF at Booth #2521!  
Exhibits are open: Sunday, October 27 – 10:00 am – 5:00 pm  
Monday, October 28 – 10:00 am – 5:00 pm  
Tuesday, October 29 – 10:00 am – 2:30 pm
12th International Symposium on Sjögren's Syndrome

New Era on Sjögren's Syndrome

9-12 Wed-Sat
October 2013

Kyoto Hotel Okura, Kyoto, Japan

Takayuki Sumida
Professor, Department of Internal Medicine,
University of Tsukuba

Organized by: Department of Internal Medicine, University of Tsukuba
Japanese Society for Sjögren's Syndrome

www.12isss.com
Interstitial cystitis (also known as IC) is a chronic bladder condition that usually consists of recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region, urinary frequency (needing to go often) and urgency (feeling a strong need to go). IC also may be referred to as painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain (CPP). The exact cause is unknown, but researchers have identified different factors that may contribute to the development of the condition. About 25% of IC patients have a definite or probable diagnosis of Sjögren’s, and as many as 14% of Sjögren’s patients are estimated to have IC.

### Some things you can do to control your IC include:

- Avoid or limit foods and beverages that may irritate the bladder, including coffee, tea, soda, alcohol, citrus juices, and cranberry juice. For some, spicy foods may be a problem as well as foods and beverages containing artificial sweeteners.
- Apply heat or cold over the bladder or between the legs to alleviate some pain.
- Modify or stop Kegel exercises which may make pelvic floor muscles even tighter.
- Avoid tight clothing to prevent further irritation and restricted blood flow to the pelvic region.
- Treat constipation. It can add pressure to the pelvic area and increase pain and discomfort.
- Develop healthy sleep habits as sleep is crucial for pain control.
- Adjust fluid intake. Increase or decrease depending on your situation.
- Retrain your bladder by learning to urinate on a set schedule and not when your bladder tells you.
- Find healthy ways to manage your stress since it may make IC symptoms worse.
- Find, in advance, the location of restrooms along your route when traveling.
- Get active! The health of your bladder depends on good blood flow to the area and on having flexible and strong muscles around your bladder and other pelvic organs to protect and support them.
- Quit smoking. Cigarettes may irritate the bladder and worsen pelvic and bladder pain.
- Take a trial and error approach to treatment as no one treatment works for everyone. A combination of treatments is often necessary to get your IC under control.
- Track how your symptoms change with treatment and speak with your healthcare provider if you think a therapy is not working.

Visit the Interstitial Cystitis Association website, www.ichelp.org, for the most up-to-date and accurate information about IC and to find knowledgeable healthcare providers.
Going to the ACR?

Visit Us at Booth #2521!

Exhibits are open: Sunday, October 27 – 10:00 am – 5:00 pm
Monday, October 28 – 10:00 am – 5:00 pm
Tuesday, October 29 – 10:00 am – 2:30 pm

Sessions on Sjögren’s!

- Pre-Meeting Course: Epigenetics of Autoimmune Disease – MicroRNA Expression Profiles in Sjögren’s Syndrome – Illias Alevizos, DMD, MMSc
- Meet the Professor: Controversies in Sjögren’s Syndrome – Alan N. Baer, MD — Advance registration required
- ACR Study Group: Sjögren’s Syndrome – Jacques-Eric Gottenberg, MD, Moderator
- Oral Health in Rheumatologic Disease: What Every Rheumatology Practitioner Should Know About Oral Health and Diseases – Parish P. Sedghizadeh, DDS, MS
- Oral Health in Systemic Lupus Erythematosus and Sjörgens – Daniel Wallace, MD
- Oral Health and Osteoporosis Therapy – Stuart L. Silverman, MD
- Current Management of Sjögren’s Syndrome
  - Management of Dry Eye Disease in Sjögren’s Syndrome – George Papaliodis, MD
  - Oral and Dental Care of the Patient with Sjögren’s Syndrome – Ava Wu, DDS
  - Emerging Role of Biologic Agents in Sjögren’s Syndrome – E. William St. Clair, MD