

The Moisture Seekers



Sjögren's
SS
F
Syndrome
Foundation

www.sjogrens.org

Volume 31, Issue 3

March 2013

f SjogrensSyndromeFoundation

@MoistureSeekers



Living with Chronic Pain

by Darlene Cross, MS, MFT

Work with many brave souls who battle chronic pain in their day-to-day lives. These patients are at war with a varying number of diagnoses, from autoimmune disorders to neurological impairments, everything in between, and sometimes more than one at the same time. I have seen the benefits of counseling or psychotherapy as part of overall treatment, but today I want to discuss what I have too often seen that does not help. I also want to share some proven ideas for getting and staying on the right track.

It is not unusual for some illnesses involving chronic pain to take years to find an accurate diagnosis. Patients may see a

continued page 2 ▼

Vitamin D: A Link with Peripheral Neuropathy and Lymphoma

by Nancy Agmon-Levin, MD and Yehuda Shoenfeld, MD
Zabludowicz Center for Autoimmune Diseases, The Chaim Sheba Medical Center, Tel Hashomer, Israel

Vitamin D and Sjögren's

Sjögren's syndrome (SS) is a slowly progressing autoimmune disease affecting the exocrine glands of predominantly middle aged women. The prevalence of SS is reported to be between 0.1 and 4.8% depending on different reports from different geographical and ethnical areas.^{1,2} Extra glandular manifestations appear in up to half of the patients with SS, may involve the joints, skin, lung, central and peripheral nervous system, and may associate with various auto-antibody profiles.³ An increased incidence of lymphoma in SS patients, mainly of B-cell origin, is repeatedly demonstrated in large epidemiological studies.^{4,5}

Due to the wide involvement of vitamin D in different autoimmune diseases, we decided to determine the levels and the impact of vitamin D in 176 primary Sjögren's syndrome (pSS) patients and 163 matched healthy volunteers.⁶ A correlation between vitamin D levels and clinical and serological manifestations of SS was performed. To our great surprise, we did not find

continued page 4 ▼

In This Issue

3 I Stood Up

8 Awareness Challenge

11 In Memory & In Honor

12 Breakthrough Bullet



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

e-mail: tms@sjogrens.org
www.sjogrens.org

"Chronic Pain" continued from page 1 ▼

dozen or more doctors while seeking help, answers and relief. Some may have multiple medical appointments in the span of just one week. They may see different specialists for different symptoms, as if body parts function independently of one another. The patient may be on many medications, coping with side effects that can be brutal, and too many of these services focus on what the patient cannot do with little or no attention paid to what they can do. The very process can leave the patient feeling more helpless, more depressed, more fatigued, more stressed. How frustrating must it be to have the very things you do to get better and regain control of your life make you worse?

If you or someone you know is one of these patients, here are some tried-and-true ideas that have helped others that you also may find helpful:

- First, do not settle for bad medicine. Acknowledging that these cases do not fit well into today's quick medical model, if you do not feel heard or helped, find another doctor. If that doctor does not meet your needs, find another doctor. Bear in mind that cheapest in the short run may end up being the most expensive long term if you are not getting good results. There are many good, skilled and caring doctors, but it may take some time to find the right one for you. The physician who is willing to be your partner and your educator and treat you with dignity and respect is the right choice for you.
- Be your own advocate. No one knows your body better than you. No one knows your pain better than you. No one knows what makes you happy better than you. You are the expert on you.
- Resist buying into the idea that our medical system is so broken good treatment is not available. I will never debate the idea that the system is broken. I will debate the idea that good treatments are not available. It may require defining and redefining what constitutes "good treatment" as you figure out what works best for you, but you will know it when you find it.
- Just because a treatment may be considered "holistic" does not mean it does not have value. Just because something is approved by your insurance company does not mean it does have value. Neither comes with any guarantee and both should be met with healthy skepticism. Leaving any positive option out of the mix is a missed opportunity.
- Remember to pay as much attention to your mental health as you do your physical health. The mind-body connection is real and plays a major role in combating any illness.
- Consider limiting the number of medical appointments you have in one week, if at all possible. Too much focus on what ails you can bring down the best mood and invite in the boogeyman at 3:00 a.m. with dark thoughts that never helped anyone. Too many appointments also can eat up time that would have been available for a yoga class, a trip to the gym, or lunch with a good friend. Balance is important.

continued page 7 ▼

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...

Feeling Bold?

Like many Sjögren's patients, Judy had kept her disease private, not sharing openly that she was living with Sjögren's. In 2011, however, that changed when she fainted and had to be taken to the Emergency Room (ER). Despite being barely coherent, Judy had to tell the doctor at the ER that she had Sjögren's and then had to explain to him what it was since he was not familiar, which is unfortunately common. In that moment, Judy knew that she had to be a voice for Sjögren's. In that moment, Judy knew that she had to be a voice for Sjögren's.

As a 5th grade teacher at Prairie Point Elementary, Judy noticed the Bold Blue Day flyer in an issue of *The Moisture Seekers* newsletter and knew it was something she wanted to do. She worked with her school principal and picked a Friday in April where every student and faculty member could donate \$5 to dress casual in their blue jeans and were given an SSF sticker to show their participation.

Initially, Judy was very nervous about promoting the Bold Blue Day and worried that people outside of her direct 5th grade team wouldn't participate, but was overwhelmed with support and how many people came up and asked her about Sjögren's. One of the teachers had a substitute for the day, but let her know ahead of time that it was Bold Blue Day. The substitute came to her classroom dressed in a blue shirt and jeans with her \$5 participation fee and then stayed to ask Judy about Sjögren's and if she could have a "What is Sjögren's" brochure that was sent with the Bold Blue Day Kit from the SSF. While everyone at Prairie Point Elementary enjoyed a fun day in casual clothes, they also learned about Sjögren's and little more about Judy.

Bold Blue Day is now an annual event for Prairie Point Elementary and their participation recognition from the Sjögren's Syndrome Foundation was even featured in their faculty newsletter. Thank you Judy for feeling bold and informing your community about Sjögren's.

If you want to host a Bold Blue Day this April – just contact the Sjögren's Syndrome Foundation at 800-475-6473 Ext 227. Remember that it doesn't have to be your employer who holds the fundraiser! You can ask family members or friends to get their employers to host a Bold Blue Day in your honor. Even consider asking local businesses to participate too! It's a great way to bring awareness directly to your community while also raising funds for Sjögren's research and awareness.

Are you feeling BOLD? Contact us today! ■



I will Stand Up in 2013!

"Vitamin D" continued from page 1 ▼

a significant difference between patients with SS and the controls on the absolute levels of vitamin D. This contrasts with the widespread low levels detected in our large number of patients with other autoimmune conditions. Yet, when we analyzed the levels compared to different clinical manifestations, again to our great surprise, we found a strong relation between low levels of vitamin D and the presence of peripheral neuropathy. Furthermore, another clinical aspect in which correlation between low levels or very low levels of vitamin D and its presence was found in lymphoma. These are important clinical findings which may determine the treatment and prognosis of patients with Sjögren's.

Vitamin D and Neuropathy

The impact of vitamin D on neuronal cells is well recognized.⁷ Vitamin D receptors have been located within glial cells and are linked to the reduction of schwann cell inflammation. Moreover, vitamin D was shown to up-regulate the gene expression of nerve growth factor.⁷ Chabas *et al.*⁸ demonstrated that vitamin D2 can potentiate axon regeneration in the rat peroneal nerve. Vitamin D deficiency is related to impaired neuromuscular function among patients with chronic pain,⁹ and a high prevalence of vitamin D deficiency is demonstrated in patients with diabetic peripheral neuropathy.¹⁰ Additionally, its supplementation was found to be effective for pain alleviation in diabetic patients with neuropathic pain.^{11,12} Overall, it seems that vitamin D deficiency may be a component in the pathogenesis of neuropathy in pSS and may be used for monitoring and treatment of this condition.

Lymphoma and Vitamin D

The connection of several autoimmune diseases and lymphoproliferative disorders is well documented and several mechanisms have been proposed.¹³ Patients with pSS are at a 9e16-fold increased risk for non-Hodgkin lymphoma (NHL) compared to healthy population,¹⁴ and the prevalence is estimated to be 4e5%.¹⁵ Previous studies are in line with our results demonstrating an increased risk for lymphoma in pSS patients presenting with purpura, decreased C4 complement levels, and mixed monoclonal cryoglobulinemia.¹⁶ Other factors such as CD4 β T lymphopenia and a low CD4 β /CD8 β T-cell ratios have been also reported by others. Two parameters that were previously associated with lymphoma in pSS patients were not assessed in this cohort (persistent salivary gland enlargement and leg ulcer).

Summary on Sjögren's and Vitamin D

In summary the correlation between low levels of vitamin D, neuropathy, and lymphoma in SS patients may have

practical implications, since vitamin D is very cheap and even large doses taken daily (2,000 units/day) may have no side effects whatsoever. The practical lesson may be to instruct each patient with Sjögren's to take 2,000 units/day of vitamin D either to prevent the eventual development of neuropathy as well as probably to prevent the eventual development of the serious complication of lymphoma.

Autoimmunity and Vitamin D

The mosaic of autoimmunity is comprised of a complicated interplay between endogenous and exogenous factors such as genetic, hormonal and environmental ones. Vitamin D has been recognized as both an exogenous and endogenous player.¹⁷

Vitamin D is a fat-soluble pro-hormone found in significant amounts in certain fish and in small amounts in other ingredients of the western diet. It is synthesized in large quantities in skin exposed to UV rays of sunlight. Following the syntheses of vitamin D, it is converted in vivo into biologically active metabolites namely 25(OH)D and 1,25(OH)D.¹⁸ The latter regulate numerous functions in various cell types, through binding to vitamin D receptors (VDR) on both calcemic and noncalcemic tissues.¹⁸ Thus, upon activation of VDRs, they not only control calcium metabolism but also elicit a wide variety of biological responses which influence cellular growth, proliferation, apoptosis, and immune modulation.^{19,20}

Vitamin D binds to VDRs on various cells participating in immune responses, thereby modulating both the activation and deactivation of the innate and adaptive responses.^{20,21} For instance, Vitamin-D may induce innate tolerance by promoting tolerogenic dendritic cells on the one hand while on the other induce a robust macrophage response to infections (i.e. mycobacterium tuberculosis).^{18,22} Additionally, both humoral and cellular adaptive responses are affected by vitamin D.

Decreased proliferation and antibody production by B-cells have been documented following exposure to vitamin D.²³ While the later effect on the cellular response is comprised of a switch from Th1 to Th2 cytokine profile, ameliorating Th17 pathway via transcriptional modulation of interleukin-17A as well as induction of T regulatory cells and immune tolerance.^{19,24,25} In this context, seasonal variation in vitamin D levels were reported to parallel changes in peripheral blood human T cell compartment.²⁶

Geo-epidemiology, sunlight exposure & vitamin-D

Determination of vitamin-D status is preformed via measurements of 25(OH)D serum levels.¹⁸ In the last decade, the recommended levels of vitamin-D (25OH) have been an issue of great debate. Currently, it is accepted

continued page 6 ▼



Order These Great Resources Today!

	Non-Member Price	Member Price	Qty	Amount
The Sjögren's Book, Fourth Edition: <i>edited by Daniel J. Wallace, MD.</i> The 2011 edition of the Sjögren's handbook has been completely revised and expanded with all new chapters and the latest information on Sjögren's.	\$32	\$28		
The Sjögren's Syndrome Survival Guide by <i>Teri P. Rumpf, PhD, and Kathy Hammitt.</i> A complete resource for Sjögren's sufferers, providing medical information, research results, and treatment methods as well as the most effective and practical self-help strategies.	\$15	\$13		
A Body Out of Balance by <i>Ruth Fremes, MA, and Nancy Carteron, MD, FACR.</i> A Sjögren's patient and a doctor offer their authoritative insight into one of the most common yet most misunderstood autoimmune disorders.	\$13	\$10		
Dancing at the River's Edge: A Patient and her Doctor Negotiate Life with Chronic Illness by <i>Alida Brill and Michael D. Lockshin, MD.</i> A dual memoir with a patient and her doctor that offers a powerful and inspirational testimony from either side of the examining table.	\$16	\$14		
Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won't Stop by <i>Norman Latov, MD, PhD.</i> Peripheral neuropathy is a widespread disease, yet many people do not even realize they have it. If you experience pain, numbness, or tingling in your feet or other extremities, this book is for you.	\$19	\$16		
You Can Cope with Peripheral Neuropathy: 365 Tips for Living a Full Life by <i>Mims Cushing and Norman Latov, MD.</i> A compendium of tips, techniques, and life-task shortcuts that will help everyone who lives with this painful condition.	\$19	\$16		
Vulvodynia Survival Guide: How to Overcome Painful Vaginal Symptoms & Enjoy an Active Lifestyle by <i>Howard I. Glazer, PhD and Gae Rodke, MD, FACOG.</i> A great resource for anyone experiencing vulvodynia symptoms. This book will help readers identify triggers, reduce symptoms, find medical help, reduce pain, and renew their enjoyment of life.	\$16	\$13		
The Woman's Book of Sleep: A Complete Resource Guide by <i>Amy Wolfson, PhD.</i> An overview of the latest findings pertinent to women's sleep, and it distills their practical implications in a direct and straightforward style.	\$16	\$13		
The Memory Bible: An Innovative Strategy for Keeping Your Brain Young by <i>Gary Small, MD.</i> This program has helped thousands of people improve their ability to remember everyday issues like where their car is parked as well as more important abilities to think fast and maintain a healthy brain.	\$16	\$13		
Purchase a full set of last year's <i>Moisture Seekers</i> newsletter Volume 30, 2012 (11 issues) as originally published.	\$50	\$20		
Maryland Residents add 6% sales tax				
Shipping and Handling: US Mail: \$5 for first item + \$3 for each additional item Canada: \$14 for first item + \$2 for each additional item Overseas: \$22 for first item + \$2.50 for each additional item				
Please consider an additional contribution: <input type="checkbox"/> \$25 <input type="checkbox"/> \$50 <input type="checkbox"/> \$75 <input type="checkbox"/> \$100 <input type="checkbox"/> \$250 <input type="checkbox"/> \$500 <input type="checkbox"/> Other: _____				
Join now and SAVE on your purchase! (Apply member pricing to all items.) Membership – Includes a subscription to <i>The Moisture Seekers</i> newsletter. Member dues (US dollars): <input type="checkbox"/> \$32 US <input type="checkbox"/> \$59 2-year membership option <input type="checkbox"/> \$38 Canada <input type="checkbox"/> \$45 Overseas <input type="checkbox"/> \$50 Healthcare professional				
Total Amount				

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 US funds only, drawn on a US bank, net of all bank charges) payable to SSF.

MasterCard VISA Discover AmEx Card Number _____ Exp. Date _____

Signature _____ Security Code _____

SSF_13119.05/2013

"Vitamin D" continued from page 4 ▼

that maintaining serum 25-OH vitamin-D concentration at a level of 30 ng/ml (80 nmol/l) or more is beneficial for maintaining bone health and calcium homeostasis,^{18,27} whereas the levels required to maintain noncalcemic functions of vitamin-D are yet unknown.²⁸ Low levels of vitamin-D (below 20 ng/ml) have been documented in healthy and diseased population worldwide mainly in northern climate.²⁹ However in the last decade, probably due to changes in life habits, even in sunny climates healthy subject present with lower levels of vitamin-D.³⁰

Epidemiological data underline a strong correlation between poor vitamin-D status and higher risk for chronic illnesses of various etiologies, including cancers, autoimmune diseases, cardiovascular morbidity, diabetes and infectious diseases.²⁷ [A case in point is infection with mycobacterium tuberculosis (TB). Decades ago patients with tuberculosis were sent to convalesce in sanatoriums being exposed to sunlight, and the mechanisms by which vitamin-D affects the immune responses to TB have been elucidated.²² Intriguingly, infection with TB has been linked with the presence of autoantibodies and autoimmune diseases both of which may be affected by vitamin-D status.²²

In parallel increase in the incidence of autoimmunity has been documented in the last decades, and an association between low sun exposure inducing lower vitamin-D and higher prevalence of certain autoimmune diseases was observed.^{28,31,32} Furthermore, several autoimmune diseases, including inflammatory bowel disease, multiple sclerosis, type I diabetes, and rheumatoid arthritis (RA), have been documented to be more prevalent in Northern latitudes where sun exposure is reduced.^{33,34}

From a Vitamin to Immunomodulator

Vitamin D was originally revealed as a vitamin needed in small amounts to affect the metabolism of calcium and phosphor. Like other vitamins in the lack of this important compound a disease ensued which in this case was the Rickets. Since the definition of the roles of vitamin D at least in the modern world Rickets was almost eradicated. Thousands of studies carried out to decipher the role of Vitamin D in our body led to the definition of its receptors in almost any cell and tissue in our body thus leading to its remote effects on different organs. These remote aspects and the fact that active vitamin D circulates in the blood brought to a new definition of a vitamin as a hormone.

Among the many important cells and tissues in which the vitamin D receptors (VDR) were revealed are the immune cells: lymphocytes, monocytes and dendritic

cells, therefore the next step that emerged especially during the last decade was exposing the role of vitamin D as a positive immunomodulator on the immune system, indicating the impact of the lack of the vitamin in the pathogenesis of immunomediated diseases on the one hand and the significant role of pharmacological doses of vitamin D in autoimmune diseases. So far more than 30 positive effects of Vitamin D on the immune system have been reported.^{17,35-38}

The close relationship with the production of the active ingredient of vitamin D upon exposure to UV light (i.e. sun exposure) was well known for years. For instance, patients with tuberculosis in the olden days were sent to a sanatorium to benefit from exposure to the sun in combating the mycobacterium tuberculosis. Only recently has the beneficial effect of vitamin D on macrophages in phagocytizing the mycobacterium tuberculosis been detailed.³⁹ Modern life is characterized by not being exposed too much to the sun, staying in closed rooms (air conditioning), watching television, etc. Therefore, it is not surprising that when analyzing the level of vitamin D in the blood of healthy subjects in a sunny country like Israel, we found that there was no difference between summer and winter figures and moreover that the levels were commonly very low. We have a series of studies indicating low levels of vitamin D not only in healthy subjects but more prominently in a series of patients with diverse autoimmune diseases such as systemic sclerosis, Sjögren's, autoimmune thyroid disease, celiac disease, SLE and MCTD.⁶ ■

References

- 1 Mavragani CP, Moutsopoulos HM. The geoepidemiology of Sjögren's syndrome. *Autoimmun Rev.* 2010;9:A305-10.
- 2 Tzioufas AG, Vlachoyiannopoulos PG. Sjögren's syndrome: an update on clinical, basic and diagnostic therapeutic aspects. *J Autoimmun.* 2012 Aug;39(1-2):1-3.
- 3 Bournia VK, Vlachoyiannopoulos PG. Subgroups of Sjogren syndrome patients according to serological profiles. *J Autoimmun.* 2012 Aug;39(1-2):15-26.
- 4 Ioannidis JP, Vassiliou VA, Moutsopoulos HM. Long-term risk of mortality and lymphoproliferative disease and predictive classification of primary Sjögren's syndrome. *Arthritis Rheum.* 2002;46:741-7.
- 5 Theander E, Henriksson G, Ljungberg O, Mandl T, Manthorpe R, Jacobsson LT. Lymphoma and other malignancies in primary Sjögren's syndrome: a cohort study on cancer incidence and lymphoma predictors. *Ann Rheum Dis.* 2006; 65:796-803.
- 6 Agmon-Levin N, Kivity S, Tzioufas AG, López Hoyos M, Rozman B, Efes I, Shapira Y, Shamis A, Amital H, Youinou P, Shoenfeld Y. Low levels of vitamin-D are associated with neuropathy and lymphoma among patients with Sjögren's syndrome. *J Autoimmun.* 2012 Sep;39(3):234-9. doi: 10.1016/j.jaut.2012.05.018.
- 7 Kiraly SJ, Kiraly MA, Hawe RD, Makhani N. Vitamin D as a neuroactive substance: review. *ScientificWorldJournal.* 2006;6:125-39.
- 8 Chabas JF, Alluin O, Rao G, Garcia S, Lavaut MN, Rizzo JJ, et al. Vitamin D2 potentiates axon regeneration. *J Neurotrauma.* 2008;25:1247-56.
- 9 Turner MK, Hooten WM, Schmidt JE, Kerkvliet JL, Townsend CO, Bruce BK. Prevalence and clinical correlates of vitamin D inadequacy among patients with chronic pain. *Pain Med.* 2008;9:979-84.

- 10 Skalli S, Muller M, Pradines S, Halimi S, Wion-Barbot N. Vitamin D deficiency and peripheral diabetic neuropathy. *Eur J Intern Med.* 2012;23:67-8.
- 11 Valensi P, Le Devehat C, Richard JL, Farez C, Khodabandehlou T, Rosenbloom RA, *et al.* A multicenter, double-blind, safety study of QR-333 for the treatment of symptomatic diabetic peripheral neuropathy. A preliminary report. *J Diabetes Complications.* 2005;19:247-53.
- 12 Lee P, Chen R. Vitamin D as an analgesic for patients with type 2 diabetes and neuropathic pain. *Arch Intern Med.* 2008;168:771-2.
- 13 Mackay IR, Rose NR. Autoimmunity and lymphoma: tribulations of B cells. *Nat Immunol.* 2001;2:793-5.
- 14 Smedby KE, Baecklund E, Askling J. Malignant lymphomas in autoimmunity and inflammation: a review of risks, risk factors, and lymphoma characteristics. *Cancer Epidemiol Biomarkers Prev.* 2006;15:2069-77.
- 15 Peri Y, Agmon-Levin N, Theodor E, Shoenfeld Y. Sjögren's syndrome, the old and the new. *Best Pract Res Clin Rheumatol.* 2012;26:105-17.
- 16 Skopouli FN, Dafni U, Ioannidis JP, Moutsopoulos HM. Clinical evolution, and morbidity and mortality of primary Sjögren's syndrome. *Semin Arthritis Rheum.* 2000;29:296-304.
- 17 Arnsen Y, Amital H, Shoenfeld Y. Vitamin-D and autoimmunity: new etiological and therapeutic considerations. *Ann Rheum Dis.* 2007 Sep;66(9):1137-42.
- 18 Holick MF. Vitamin-D deficiency. *N Engl J Med.* 2007 Jul 19;357(3):266-81.
- 19 Peelen E, Knippenberg S, Muris AH, Thewissen M, Smolders J, Tervaert JW, *et al.* Effects of vitamin-D on the peripheral adaptive immune system: a review. *Autoimmun Rev.* 2011 Oct;10(12):733-43.
- 20 Toubi E, Shoenfeld Y. The role of vitamin-D in regulating immune responses. *Isr Med Assoc J.* 2010 Mar;12(3):174-5.
- 21 Pelajo CF, Lopez-Benitez JM, Miller LC. Vitamin-D and autoimmune rheumatologic disorders. *Autoimmun Rev.* 2010 May;9(7):507-10.
- 22 Shapira Y, Agmon-Levin N, Shoenfeld Y. Mycobacterium tuberculosis, autoimmunity, and vitamin-D. *Clin Rev Allergy Immunol.* 2010 38(2-3):169-77.
- 23 Chen S, Sims GP, Chen XX, Gu YY, Lipsky PE. Modulatory effects of 1,25-dihydroxyvitamin-D3 on human B cell differentiation. *J Immunol.* 2007 Aug 1;179(3):1634-47.
- 24 Cutolo M, Plebani M, Shoenfeld Y, Adorini L, Tincani A. Vitamin-D endocrine system and the immune response in rheumatic diseases. *Vitam Horm.* 2011;86:327-51.
- 25 Joshi S, Pantalena LC, Liu XK, Gaffen SL, Liu H, Rohowsky-Kochan C, *et al.* 1,25-dihydroxyvitamin-D(3) ameliorates Th17 autoimmunity via transcriptional modulation of interleukin-17A. *Mol Cell Biol.* 2011 Sep;31(17):3653-69.
- 26 Khoo AL, Koenen HJ, Chai LY, Sweep FC, Netea MG, van der Ven AJ, *et al.* Seasonal variation in vitamin-D(3) levels is paralleled by changes in the peripheral blood human T cell compartment. *PLoS One.* 2012;7(1):e29250.
- 27 Souberbielle JC, Body JJ, Lappe JM, Plebani M, Shoenfeld Y, Wang TJ, *et al.* Vitamin-D and musculoskeletal health, cardiovascular disease, autoimmunity and cancer: Recommendations for clinical practice. *Autoimmun Rev.* 2010 Sep;9(11):709-15.
- 28 Broder AR, Tobin JN, Putterman C. Disease-specific definitions of vitamin-D deficiency need to be established in autoimmune and non-autoimmune chronic diseases: a retrospective comparison of three chronic diseases. *Arthritis Res Ther.* 2010;12(5):R191.
- 29 Shoenfeld N, Amital H, Shoenfeld Y. The effect of melanism and vitamin-D synthesis on the incidence of autoimmune disease. *Nat Clin Pract Rheumatol.* 2009 Feb;5(2):99-105.
- 30 Oren Y, Shapira Y, Agmon-Levin N, Kivity S, Zafrir Y, Altman A, *et al.* Vitamin-D insufficiency in a sunny environment: a demographic and seasonal analysis. *Isr Med Assoc J.* 2010 Dec;12(12):751-6.
- 31 Shapira Y, Agmon-Levin N, Shoenfeld Y. Defining and analyzing geoepidemiology and human autoimmunity. *J Autoimmun.* 2010 May;34(3):J168-77.
- 32 Carmi G, Amital H. The geoepidemiology of autoimmunity: capsules from the 7th International Congress on Autoimmunity, Ljubljana, Slovenia. *Isr Med Assoc J.* 2011 Feb;13(2):121-7.
- 33 Miheller P, Muzes G, Hritz I, Lakatos G, Pereg I, Lakatos PL, *et al.* Comparison of the effects of 1,25 dihydroxyvitamin-D and 25 hydroxyvitamin-D on bone pathology and disease activity in Crohn's disease patients. *Inflamm Bowel Dis.* 2009 Nov;15(11):1656-62.
- 34 Cutolo M, Pizzorni C, Sulli A. Vitamin-D endocrine system involvement in autoimmune rheumatic diseases. *Autoimmun Rev.* 2011 Dec;11(2):84-7.
- 35 Carvalho ZF, Blank M, Kiss E, Tarr T, Amital H, Shoenfeld Y. Anti-Vitamin D, Vitamin D in SLE preliminary results. *Ann NY Acad Sci.* 2007;1109: 550-7.
- 36 Orbach H, Zandman-Goddard G, Amital H, Barak V, Szekanez Z, Szucs G, Danko K, Nagy E, Csepány T, Carvalho JF, Doria A, Shoenfeld Y. Novel biomarkers in autoimmune diseases. Prolactin, Ferritin, Vitamin D and TPA levels in autoimmune diseases. *Ann NY Acad Sci.* 2007; 1109: 385-400.
- 37 Shoenfeld N, Amital H, Shoenfeld Y. The effect of melanism and vitamin D synthesis on the incidence of autoimmune disease. *Nature Rheumatol.* 2009;5: 99-105.
- 38 Shapira Y, Agmon-Levin N, Shoenfeld Y. Mycobacterium tuberculosis, autoimmunity, and Vitamin D. *CRAI- Clin Rev Allerg Immunol.* 2010;38: 169-77.
- 39 Martineau AR, Wilkinson RJ, Wilkinson KA, Newton SM, Kampmann B, Hall BM, Packe GE, Davidson RN, Eldridge SM, Maunsell ZJ, Rainbow SJ, Berry JL, Griffiths CJ. A single dose of vitamin D enhanced immunity to mycobacteria. *Am J Respir Crit Care Med.* 2007 Jul; 176(2):208-13.

"Chronic Pain" continued from page 2 ▼

- I know you've heard this one before: You are what you eat. A deprivation diet is not necessary or helpful or sustainable, but a healthy diet filled with a rainbow of foods that are good for all of us are even more important for those with special needs. Consider including a qualified nutritionist in your treatment team.
- Take a relationship inventory. If you have people around you who drag you down, who think they know what is best for you better than you and your doctors, or who may even question the reality of your illness, it's time to clean house. The drain of toxic people and toxic relationships sucks away energy better used in creating your best possible life.
- Whatever you love doing, do it – and then, do it again.



sip for
Sjögren's
a fine water
tasting event

Host an event in your area... We'll help.

If you are interested in organizing a Sip for Sjögren's event in your area, please contact Sheriese DeFruscio, Vice President of Development, 800-475-6473 ext 212 or sdefruscio@sjogrens.org.



Awareness Challenge: Tell 5 or Tell 50!

April is Sjögren's Awareness Month and keeping with our *5-Year Breakthrough Goal*, we're holding our first ever **AWARENESS CHALLENGE!**

The SSF knows how difficult and often discouraging it can be to talk about Sjögren's with your friends, family and co-workers, and always having to answer the question - "What is Sjögren's?"

That is why we are asking every SSF member to take our challenge and tell just 5 people in your life about Sjögren's. We know that sharing can be scary at first, but you'll never know what support you'll receive until you start! That is why we are challenging you with telling 5 people about Sjögren's and who knows, you might just be inspired to tell 50! Take our challenge and let us know how many people in your life now know about Sjögren's thanks to YOU!

Tell 5 or tell 50 and watch Sjögren's awareness grow!

Not sure how to begin? Here are a few suggestions:

- Start with a simple statement like "Did you know April is Sjögren's Awareness Month? And then explain to them that Sjögren's is an autoimmune disease in which the body's immune system attacks the moisture-producing glands. Along with symptoms of dryness, it can affect any body organ or system and spread throughout the entire body causing joint pain, fatigue and other symptoms.
- If you are comfortable – tell them that you have Sjögren's or feel free to not share but just telling them about Sjögren's is helping us increase awareness.
- Visit our website where you can download a short fact sheet to handout to everyone you tell!
- Consider purchasing SSF Awareness Bracelets to give to those you tell!
- And finally – fill in the form on the attached page so that you can be entered into our drawing!

And as always – contact the SSF with any questions. Just call 800-475-6473 ext 216. Together – one by one – we will increase awareness this April!



2013 AWARENESS CHALLENGE

Tell 5 or tell 50 and watch Sjögren's awareness grow!

Please send the form below back to the SSF with the names of 5 or 50 friends that you've informed about Sjögren's because of this challenge by May 1st and be entered to win a membership to the SSF!

Mail your completed form back by May 1st to the SSF office:

Sjögren's Syndrome Foundation
Attn: "Awareness Challenge"
6707 Democracy Blvd., STE 325
Bethesda, MD 20817

One person at a time, one community at a time - if we all participate imagine how quickly we could increase Sjögren's awareness. Together we will conquer Sjögren's!

Your Name: _____

Your Address: _____

Your Email Address: _____

TELL 5 and be entered to win a five-year membership to the SSF

I stepped up for Sjögren's by sharing with:

Mary Martin (SAMPLE)

- | | | |
|-----------|-----------|-----------|
| 1. _____ | 18. _____ | 37. _____ |
| 2. _____ | 19. _____ | 38. _____ |
| 3. _____ | 20. _____ | 39. _____ |
| 4. _____ | 21. _____ | 40. _____ |
| 5. _____ | 22. _____ | 41. _____ |
| 6. _____ | 23. _____ | 42. _____ |
| 7. _____ | 24. _____ | 43. _____ |
| 8. _____ | 25. _____ | 44. _____ |
| 9. _____ | 26. _____ | 45. _____ |
| 10. _____ | 27. _____ | 46. _____ |
| 11. _____ | 28. _____ | 47. _____ |
| 12. _____ | 29. _____ | 48. _____ |
| 13. _____ | 30. _____ | 49. _____ |
| 14. _____ | 31. _____ | 50. _____ |
| 15. _____ | 32. _____ | |
| 16. _____ | 33. _____ | |
| 17. _____ | 34. _____ | |
| | 35. _____ | |
| | 36. _____ | |

TELL 50 and be entered to win a lifetime membership to the SSF.



TEAM SJÖGREN'S... ON THE ROAD AGAIN!

**Join Team Sjögren's in Nashville,
the home of country music...**

...and the Country Music Marathon and Half-Marathon

Join *Team Sjögren's* and train to run or walk in the 2013 Country Music Marathon and Half-Marathon in Nashville on April 27, 2013.

We are looking for 30 inspired individuals to join us as we begin to train for this challenge. We understand that not all Sjögren's patients are able to run or walk in a marathon, so we hope you will help us recruit someone else – your husband, wife, sister, cousin, daughter, son or friend – and have them run in your honor!

By signing up to join *Team Sjögren's*, you not only will receive world-class training but also leadership and mentorship from past runners and staff. You will receive coaching from our Team Trainer as well as our Team Nutritionist. The staff of the SSF will help guide you through the entire process and ensure you are ready to complete either the 13.1- or 26.2-mile course!

In addition to raising awareness for Sjögren's, you also will be helping to raise crucial funds for Sjögren's research and education.

Just imagine the difference you will be making as you run or walk in honor of all Sjögren's patients!

To learn more about *Team Sjögren's*, contact Steven Taylor at 800-475-6473, ext. 211, or staylor@sjogrens.org



Team
Sjögren's

 **in memoriam**

In Memory of Bradley R. Swanson
Marlene & Ron Anastasia

In Memory of Dorothy Adams O'Brien
B.R. & Sybil Alvarado

In Memory of Rhoda Dennison
Rita Harmeyer
George & Renee Kay
SSF Los Angeles Chapter

In Memory of Ruth (Kelly) Neurath Zisk
Thomas Kelly
Raymond Szymanski

In Memory of Sarah Pruitt Palmer
Peggy Cross

In Memory of Tikvah Rumpf
Bobette Morgan

In Memory of Willie Jay Carden
Frank & Sherri Martin
Brenda & Wayne Morris

 **in honor**

In Honor of Marilyn Cohen
Scott & Mary Strong

In Honor of JoAnn Graham's 60th Birthday
Jen Graham
Kevin, Gina, and Hunter Paulson

In Honor of Ethan Faricelli's 1st Birthday
Gregory & Tanya Bartosky
Anna, John, Nicole & Alyssa Beyer
Abigail & Brady Creatore
Josh, Gallite, Jake & Lily Kestler
Allyse & Chris Scelfo

In Honor of Lisa Faricelli
Jim & Maureen Clewley

In Honor of Theresa Balzano Kinscherf
Beth Freed

In Honor of Larry & Elaine Levin's 55th Wedding Anniversary
Hannah & David Kaplan

In Honor of Jerry Wolk's Birthday
Doreen & Maurey Wolk

New Sjögren's Merchandise: **Awareness Wristbands**



By purchasing these awareness wristbands, you are helping us achieve our 5-Year Breakthrough Goal:

"To shorten the time to diagnose Sjögren's by 50% in 5 years!"

Wording: Conquering Sjögren's - www.sjogrens.org

Pack of 10 for \$15.00†
Pack of 20 for \$25.00†

Call 800-475-6473 and order yours today!

† plus \$5.00 shipping and handling



50%
in 5 years
Sjögren's
syndrome
FOUNDATION

March Breakthrough Bullet

We knew it would take an army to achieve our 5-Year Breakthrough Goal, but just imagine a future where Sjögren's is taken more seriously by the medical community as a whole. A future where Sjögren's is a household name and you helped make it happen!

An estimated 4 million Americans (1 in 70) are currently living with Sjögren's, and many suffers are still undiagnosed and struggling to figure out why their health is deteriorating. Although Sjögren's is 3 times more common than related diseases such as lupus or multiple sclerosis, general awareness of Sjögren's is low.

If more Sjögren's patients step forward, then more physicians will be compelled to become knowledgeable about Sjögren's, which will cause more researchers and pharmaceutical companies to see the need in taking an interest in Sjögren's.

The Foundation strives to be the catalyst that changes the face of Sjögren's but we cannot do it alone. With April being Sjögren's Awareness Month just around the corner, make this the time you take a stand and help the Foundation reach our Breakthrough Goal. ■

"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 1-866-887-4867

dry mouth? MedActive
Many prescription medications can cause adverse oral side effects:
• Neuroleptics (the majority)
• Antidepressants
• Antipsychotics
• Hormonal therapy
• Chemotherapy (50%)
• Blood thinners
• Anticoagulants
• Lab of drugs

For relief of oral discomfort, MedActive provides a line of oral lubricants, moisturizers, lubricates, cleans, protects & soothes.

Light-Free, Chlorine-Free, No Parabens

Register Now!

2013 SSF National Patient Conference
“Discover the Possibilities”
April 12-13, 2013

Hyatt Regency Bethesda, Bethesda, Maryland

Presentation topics will include:

Overview of Sjögren's Syndrome
Sex and Living with Sjögren's
Biologic Therapies and Sjögren's
Understanding Blood Changes and Test Results
Caregiver/Patient Perspective on Sjögren's
Neurological Complications and Sjögren's
Dry Eye and Sjögren's
Dry Mouth and Sjögren's
Podiatry Issues and Sjögren's
Hope for the Future: Research Update

As a Sjögren's patient, it's easy to feel confused or overwhelmed by the abundance of information available about the illness and how it affects your body. But here is your opportunity to “Discover the Possibilities” for an educational journey to take control of your health and day-to-day living by learning from the best minds dealing with Sjögren's. This April, join fellow Sjögren's patients and their family members as well as healthcare professionals and other experts who specialize in Sjögren's at the 2013 SSF National Patient Conference in Bethesda, Maryland.

SSF programs are the best Sjögren's patient education opportunities in the country. They have helped thousands gain a better understanding of Sjögren's and will help you, too. This two-day event will feature an array of presentations from the country's leading Sjögren's experts – physicians, dentists, eye care providers, and researchers – who will help you understand how to manage all key aspects of your disease. So this April 12-13, we invite you to join with us and experience a weekend where you will “Discover the Possibilities” for heightening your understanding of Sjögren's at the 2013 National Patient Conference in Bethesda, Maryland!

Call **800-475-6473** or visit **www.sjogrens.org** today to receive the latest information.

2013 SSF National Patient Conference Topics and Speakers

Overview of Sjögren's Syndrome

Frederick B. Vivino, MD, MS, FACR, is Chief, Division of Rheumatology, Penn Presbyterian Medical Center, and Director of the Penn Sjögren's Center. He is also Associate Professor of Clinical Medicine, University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania. Dr. Vivino will present a comprehensive explanation of the range of symptoms that Sjögren's patients experience, explain their causes, and offer practical tips for managing them.

Dry Mouth and Sjögren's

Carol M. Stewart, MS, DDS, MS, is a Professor in the Division of Oral and Maxillofacial Diagnostic Sciences at the University of Florida College of Dentistry. She maintains an oral medicine practice at the College. The primary focus of her practice and research is medically-complex patients with immune and autoimmune-related disorders. Since 1995, she has served as the Director of the Center for Orphaned Autoimmune Disorders, a multi-specialty clinic at the University of Florida with a primary focus on Sjögren's, lupus, and rheumatoid arthritis. She has published extensively in the area of Sjögren's and salivary gland disorders. Dr. Stewart's presentation will provide insights into how Sjögren's impacts your oral health as well as information to help manage and minimize the effects of dry mouth issues.

Dry Eye and Sjögren's

Mina Massaro-Giordano, MD, is Associate Professor of Clinical Ophthalmology, University of Pennsylvania, Scheie Eye Institute. She is also the Co-Director of the Penn Dry Eye and Ocular Surface Center. Dr. Massaro-Giordano is an experienced cataract micro-surgeon and is actively involved in lecturing and teaching surgery to the residents at Penn. She sees a myriad of patients and has a specific interest in treating patients with "Tear Dysfunction Syndrome" (dry eye) including the use of autologous serum eye drops. Dr. Massaro-Giordano will discuss your dry eye symptoms and complications and will describe the latest methods and treatment options available for managing dry eye.

Biologic Therapies and Sjögren's

Steven E. Carsons, MD, FACR, is Chief of the Division of Rheumatology, Immunology, and Allergy at Winthrop-University Hospital in Mineola, New York. He is also Associate Chairman of the Department of Medicine at Winthrop-University Hospital, Director of Clinical and Translational Research at Winthrop Research Institute, and Professor of Medicine at Stony Brook University School of Medicine. Dr. Carsons will discuss current and emerging biological agents that may provide promise in the treatment of Sjögren's.



Caregivers and Patients:

A Perspective on Sjögren's

Join us for a lively caregiver and patient panel discussion, answering questions and offering suggestions and techniques for managing day-to-day living with Sjögren's. This informative discussion will be a conference highlight!

Podiatry Issues and Sjögren's

Barbara A. Campbell, DPM, FACFAOM, CWS, is a private practice podiatrist in Phoenix, Arizona. She is a physician member of the Arizona State Board of Podiatry Examiners and an advisory board member of the Arizona Podiatric Medicine Program at Midwestern University in Glendale, Arizona. Dr. Campbell has been in practice for 25 years and her podiatric medical practice treats patients of all ages. She has a special interest in diabetes and wound management. Her interest in Sjögren's was stimulated by her patients with Sjögren's. Dr. Campbell will enhance our understanding of podiatry issues and Sjögren's.

Sex and Living with Sjögren's

Anne E. Burke, MD, MPH, is Assistant Professor of Gynecology and Obstetrics, Johns Hopkins University School of Medicine, Bayview Medical Center, Baltimore, Maryland, and is dedicated to providing excellent care for women. Areas of special interest to Dr. Burke include general gynecology, vaginal infections and sexual dysfunction. Dr. Burke will share her knowledge of gynecological issues and sexual dysfunction for women with Sjögren's.

What Do the Numbers Mean? Understanding Blood Changes and Test Results

Guada Respicio, MD, MS, FACR, is a rheumatologist with Arthritis and Rheumatism Associates, one of the largest private rheumatology groups in the United States, in Wheaton and Rockville, Maryland. She also is Principal Investigator and Sub-Investigator for various clinical trials at The Center for Rheumatology and Bone Research, in Wheaton. Dr. Respicio will describe the blood changes typically associated with Sjögren's as well as help us understand the rationale and meaning of the tests ordered and procedures performed.

Neurological Complications and Sjögren's

Julius Birnbaum, MD, MHS, is Assistant Professor, Division of Rheumatology, and Assistant Professor, Department of Neurology, Johns Hopkins University School of Medicine, Baltimore, Maryland. He also is Associate Director at the Johns Hopkins Jerome L. Greene Sjögren's Syndrome Center. Dr. Birnbaum understands the challenges that may afflict patients with neurological complications of Sjögren's and is committed to improving the diagnosis and treatment of neuropathic pain. Dr. Birnbaum will share his insights and strategies with you.

Hope for the Future: Research Update

Steven Taylor, CEO of the Sjögren's Syndrome Foundation, will share an update on the Foundation's Research Program and the goals for 2013. You will learn about how research holds future promise, greater understanding and hope for better therapies for all Sjögren's patients.

Space is limited. Please register early!

Registration Form

Registration fees include: Lunch each day, snacks and beverages, Friday evening dinner, hand-out material from speakers and entrance to exhibit area on Friday and Saturday.



2013 NATIONAL PATIENT CONFERENCE BETHESDA, MARYLAND — APRIL 12-13, 2013

1 ATTENDEE – complete for each registrant

Attendee Name(s) _____
 Attendee Name(s) _____
 Street Address _____
 City _____ State _____ Zip _____
 Telephone _____ E-mail _____

2 FEES – please circle appropriate fee(s) (Note: Early Bird Deadline is March 18, 2013)

	March 18th and before	March 19th and after
SSF Members & Guests	\$170 per person	\$190 per person
Non-Members	\$190 per person	\$210 per person
TOTAL:		

3 PAYMENT – Mail to SSF, c/o BB&T Bank · PO Box 890612 · Charlotte, NC 28289-0612 or Fax to: 301-530-4415

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 _____

- Refund requests must be made in writing. Registrants whose written requests are received by March 22nd will receive a 75% refund. After that time, we are sorry that no refunds can be made.
- Dietary Requests: Unfortunately, we cannot accommodate all special dietary requirements. We can accommodate vegetarian or gluten-free dietary requests. If you require a vegetarian or gluten-free meal option, please contact Stephanie Bonner at the SSF office (301-530-4420, ext. 214) by April 2nd.
- A limited number of rooms are available at the Hyatt Regency Bethesda (One Bethesda Metro Center, Bethesda, MD 20814) at the SSF rate of \$129 per night plus tax if reservations are made by March 16, 2013. Call the toll-free hotel Central Reservations number at 888-421-1442 or call the Hyatt Regency Bethesda directly at 301-657-1234 and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.
- The Hyatt Regency Bethesda is approximately 18 miles from the Ronald Reagan Washington National Airport. The hotel **does not** provide a shuttle service. However, there is direct Metro subway access below the hotel to/from Reagan National Airport (Red Line/Bethesda Station). Alternate transportation suggestion: Taxi Fare / \$38 (one way).

QUESTIONS? Call 800-475-6473 or visit www.sjogrens.org

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



Coordinate a Bold Blue Day for Sjögren's!

What is Bold Blue Day?

Imagine your colleagues or classmates trading in their tailored slacks or dresses for a day in **blue jeans** or **bold blue** to raise vital funds for Sjögren's research and awareness.

Ask your company or your school (even your kid's school) to consider doing a dress down day for the SSF.

How does it work?

Each person choosing to dress down would donate a suggested amount to the SSF as their fee for participating. Some companies suggest \$5 while others companies/schools let each person decide how much they want to donate.

What if your company doesn't ever allow jeans?

Then just have a **BOLD BLUE DAY** – where on a certain day everyone chooses to wear their favorite **BOLD BLUE** outfit! Then collect donations for the SSF that day as well.

To receive more information or have a “Bold Blue Day” kit sent to you, contact Steph Hilton at (800) 475-6473 ext. 227 to receive your “Bold Blue Day” kit.