The Moisture Seekers

Sjögren's Syndrome Foundation

www.sjogrens.org

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by Steven Taylor, Chief Executive Officer

Many people contact the Foundation and ask us, how can I help? That is why, in 2010, the SSF has developed *Stand Up for Sjögren's*, a new campaign to share ideas of how you can make a difference for Sjögren's syndrome!

Over the next year, we will be calling upon you to step up and take on a new challenge to help increase awareness or raise funds for the fight against Sjögren's. We know that not everyone can attend a Sjögren's Walkabout or train to run a marathon, and that is why we will be giving you small examples of how each of you can make a difference.

Imagine if everyone in the SSF database – nearly 100,000 – each did just one small thing to increase awareness about Sjögren's. If every person did something, we could spread information about

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Surprises from Celiac Disease – Part 2

Study of a potentially fatal food-triggered disease has uncovered a process that may contribute to many autoimmune disorders

by Alessio Fasano, MD, University of Maryland School of Medicine

This is Part 2 of a two-part article. Part 1 was published in the December 2009 issue of The Moisture Seekers.

Guilt by Association

What role might antibodies to tissue transglutaminase play in this pathological response to gluten? The answer is still incomplete, but scientists have some idea of what could happen. When intestinal epithelial cells release tissue transglutaminase, B cells of the immune system ingest it—alone or complexed to gluten. They then release antibodies targeted to the enzyme. If the antibodies home to tissue transglutaminase sitting on or near intestinal epithelial cells, the antibodies might damage the cells directly or elicit other destructive processes. But no one yet knows whether they, in fact, cause such harm.

In the past nine years my colleagues and I have learned that unusual intestinal permeability also appears to participate in CD and other autoimmune diseases. Indeed, a growing body of evidence suggests that virtually the same trio of factors underpins most, and perhaps all, autoimmune diseases: an environmental substance that is presented to the body, a genetically based

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In This Issue

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tendency of the immune system to overreact to the substance and an unusually permeable gut.

Finding the Leak

It is fair to say that the theory that a leaky gut contributes to CD and autoimmunity in general was initially greeted with great skepticism, partly because of the way scientists thought of the intestines. When I was a medical student in the 1970s, the small intestine was described as a pipe composed of a single layer of cells connected like tiles with an impermeable "grout," known as tight junctions, between them. The tight junctions were thought to keep all but the smallest molecules away from the immune system components residing in the tissue underlying the tubes. This simple model of the tight junctions as inert, impermeable filler did not inspire legions of researchers to study their structure, and I was among the unenthused.

It was only an unexpected twist of fate, and one of the most disappointing moments of my career, that drew me to study tight junctions. In the late 1980s I was working on a vaccine for cholera. At that time, the cholera toxin was believed to be the sole cause of the devastating diarrhea characteristic of that infection. To test this hypothesis, my team deleted the gene encoding the cholera toxin from the bacterium Vibrio cholerae. Conventional wisdom suggested that bacteria disarmed in this way would make an ideal vaccine, because the remaining proteins on a living bacterial cell would elicit a strong immune response that would protect against diarrhea.

But when we administered our attenuated bacteria to volunteers, the vaccine provoked enough diarrhea to bar its use. I felt completely disheartened. Years of hard work were literally down the toilet, and we were faced with two unattractive options: giving up and moving on to another research project or persevering and trying to understand what went wrong. Some intuition that there was more to this story prompted us to choose the latter path, and this decision led us to discover a new toxin that caused diarrhea

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Why Replacing Wheat is Hard:

Gluten is a major reason that wheat-based baked goods are light and airy. During baking, gluten strands trap water and carbon dioxide gas (from yeast and other leavening agents) and expand. To make gluten-free items, bakers generally combine several flours (as well as starches and additives), because no single variety mimics the properties of wheat flour. This demand adds significantly to the cost of the resulting product. It also explains why gluten-free foods have a hard time rivaling their gluten-containing counterparts for taste and texture.

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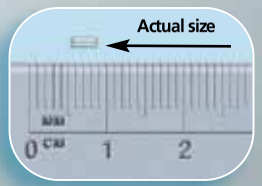

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Please see brief summary of Prescribing Information on adjacent page.

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All-Day Relief

"Surprises from CD" continued from page 2 ▼

by a previously undescribed mechanism. It changed the permeability of the small intestine by disassembling those supposedly inert tight junctions, an effect that allowed fluid to seep from tissues into the gut. This "grout" was interesting after all.

Indeed, at nearly the same time, a series of seminal discoveries clarified that a sophisticated meshwork of proteins forms the tight junctions; however, little information was available on how these structures were controlled. Therefore, the discovery of our toxin, which we called the "zonula occludens toxin," or Zot (zonula occludens is Latin for "tight junction"), provided a valuable tool for clarifying the control process. It revealed that a single molecule, Zot, could loosen the complex structure of the tight junction. We also realized that the control system that made this loosening possible was too complicated to have evolved simply to cause biological harm to the host. V. cholerae must cause diarreha by exploiting a preexisting host pathway that regulates intestinal permeability.

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LACRISERT is indicated in patients with moderate to severe dry eye syndromes, including keratoconjunctivitis sicca. LACRISERT is indicated especially in patients who remain symptomatic after an adequate trial of therapy with artificial tear solutions. LACRISERT is also indicated for patients with exposure keratitis, decreased corneal sensitivity, and recurrent corneal erosions.

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WARNINGS

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Information for Patients

Patients should be advised to follow the instructions for using LACRISERT which accompany the package. Because this product may produce transient blurring of vision, patients should be instructed to exercise caution when operating hazardous machinery or driving a motor vehicle.

Carcinogenesis, Mutagenesis, Impairment of Fertility

Feeding of hydroxypropyl cellulose to rats at levels up to 5% of their diet produced no gross or histopathologic changes or other deleterious effects.

Pediatric Use

Safety and effectiveness in pediatric patients have not been established.

Geriatric Use

No overall differences in safety or effectiveness have been observed between elderly and younger patients.

ADVERSE REACTIONS

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DOSAGE AND ADMINISTRATION

One LACRISERT ophthalmic insert in each eye once daily is usually sufficient to relieve the symptoms associated with moderate to severe dry eye syndromes. Individual patients may require more flexibility in the use of LACRISERT; some patients may require twice daily use for optimal results.

Clinical experience with LACRISERT indicates that in some patients several weeks may be required before satisfactory improvement of symptoms is achieved.

Issued June 2007

References: Kaffler BH; for the LAC-07-01 Study Group. Lacrisert (hydroxypropyl cellulose ophthalmic inserts) significantly improves symptoms of dry eye syndrome (DES) and patient quality of life. Poster presented at: Association for Research in Vision and Ophthalmology (ARVO) 2009 Annual Meeting; May 3-7, 2009; Orlando, Florida. 2. Katz JI, Kaufman HE, Breslin C, Katz IM. Slow-release artificial tears and the treatment of keratitis sicca. *Ophthalmology.* 1978;85(8):787-793. 3. Lacrisert [package insert]. Lawrenceville, NJ: Aton Pharma, Inc.; 2007. 4. Hill JC. Slow-release artificial tear inserts in the treatment of dry eyes in patients with rheumatoid arthritis. *Br J Ophthalmol.* 1989;73(2):151-154.

Five years after the formulation of this hypothesis, we discovered zonulin, the protein that in humans and other higher animals increases intestinal permeability by the same mechanism as the bacterial Zot. How the body uses zonulin to its advantage remains to be established. Most likely, though, this molecule, which is secreted by intestinal epithelial tissue as well as by cells in other organs (tight junctions have important roles in tissues throughout the body), performs several jobs—including regulating the movement of fluid, large molecules and immune cells between body compartments.

Discovery of zonulin prompted us to search the medical literature for human disorders characterized by increased intestinal permeability. It was then that we first learned, much to my surprise, that many autoimmune diseases—among them, CD, type 1 diabetes, multiple sclerosis, rheumatoid arthritis and inflammatory bowel diseases—all have as a common denominator aberrant intestinal permeability. In many of these diseases, the increased permeability is caused by abnormally high levels of zonulin. And in CD, it is now clear that gluten itself prompts exaggerated zonulin secretion (perhaps because of the patient's genetic makeup).

This discovery led us to propose that it is the enhanced intestinal permeability in CD patients that allows gluten, the environmental factor, to seep out of the gut and to interact freely with genetically sensitized elements of the immune system. That understanding, in turn, suggests that removing any one factor of the autoimmunity-causing trinity—the environmental trigger, the heightened immunity or the intestinal permeability— should be enough to stop the disease process.

Therapies to Topple the Trinity

As I mentioned before, and as this theory would predict, removing gluten from the diet ends up healing the intestinal damage. Regrettably, a lifelong adherence to a strict gluten-free diet is not easy. Gluten is a common and, in many countries, unlabeled ingredient in the human diet. Further complicating adherence, gluten-free products are not widely available and are more expensive than their gluten-containing counterparts. In addition, sticking perfectly over years to any diet for medical purposes is notoriously challenging. For such reasons, diet therapy is an incomplete solution.

Consequently, several alternative therapeutic strategies have been considered that disrupt at least one element of the three-step process. Alvine Pharmaceuticals in San Carlos, California, has developed oral protein-enzyme therapies that completely break down gluten peptides normally resistant to digestion and has an agent in clinical trials. Other investigators are considering ways to inhibit tissue transglutaminase so that it does not chemically modify undigested gluten fragments into the form where they bind so effectively to DQ2 and DQ8 proteins.

No one has yet come up with safe and ethical ways to manipulate the genes that make people susceptible to disease. But researchers are busy developing therapies that might dampen some of the genetically controlled factors that contribute to the immune system's oversensitivity. For example, the Australian company Nexpep is working on a vaccine that would expose the immune system to small amounts of strongly immunogenic forms of gluten, on the theory that repeated small exposures would ultimately induce the immune system to tolerate gluten.

With an eye toward blocking the intestinal barrier defect, I co-founded Alba Therapeutics to explore the value of a zonulin inhibitor named Larazotide. (I am now a scientific adviser for Alba and hold stock options, but I no longer participate in making decisions for the company.) Larazotide has now been tested in two human trials examining safety, tolerability and signs of efficacy in celiac patients who ate gluten. These were gold-standard trials—randomized, placebo-controlled tests in which neither the drug deliverers nor the patients know who receives treatment and who receives a sham, until the trial is over.

Together the tests showed no excess of side effects in patients given Larazotide rather than the placebo. More important, the first, smaller study demonstrated that the agent reduced gluten-induced intestinal barrier dysfunction, production of inflammatory molecules and gastrointestinal symptoms in celiac patients. And the second, large study, reported at a conference in April, showed that CD patients who received a placebo produced antibodies against tissue transglutaminase but the treated group did not. As far as I know, this result marks the first time a drug has halted an autoimmune process, interfering specifically with an immune response against a particular molecule made by the body. Other drugs that suppress immune activity act less specifically. Recently Alba received approval from the U.S. Food and Drug Administration to expand studies of Larazotide to other autoimmune disorders, including type 1 diabetes and Crohn's disease.

These new prospects for therapy do not mean that CD patients can abandon dietary restrictions anytime soon. Diet could also be used in a new way. Under the leadership of Carlo Catassi, my team at the University of Maryland has begun a long-term clinical study to test whether having infants at high risk eat nothing containing gluten until after their first year can delay the onset of CD or, better yet, prevent it entirely. "High risk," in this case, means infants possess susceptibility genes and their immediate family has a history of the disorder.

We suspect the approach could work because the immune system matures dramatically in the first 12 months of life and because research on susceptible infants has

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"Stand Up" continued from page 1 ▼

Sjögren's throughout the world. But that takes you to decide to stand up and step forward.

Here are a few examples of how you can *Stand up for Sjögren's*:

Organize an event in your area

You don't have to organize a *Sjögren's Walkabout* or *Sip for Sjögren's* – you can organize a much smaller event by yourself. For example, a bake sale at your local library or hospital, an exhibit table of information on Sjögren's at a local community center. You can hold a garage sale with proceeds to benefit the SSF or discuss with your employer about doing a dress down day at your office to increase awareness and collect donations for the SSF.

Increase Awareness

Support the SSF 2010 *Friends Helping Friends* campaign this coming April. This campaign allows you to mail letters to your friends and family, educating them about Sjögren's while also informing them about the SSF and our programs of research and education. In March, you will each be mailed six (6) letters, but if you need more, just let us know.

Use your Voice

Don't keep quiet about Sjögren's! There are so many ways you can use your voice to help the SSF. First, you can talk to your physicians and dentists about the Foundation and our free educational brochures that we have for them. Refer them to our office to get their copies. You can also use your voice to educate your family and friends. Share with them how you, and others who you know, suffer from this debilitating disease. Show them our literature, or better yet, have our *Sjögren's Syndrome Handbook* on your coffee table so house guests can see the seriousness of this disease.

Get Connected

Take part in an event or conference. We have scheduled over 10 Sjögren's Walkabouts around the United States this year as well as 11 *Sip for Sjögren's* events. Visit our website to find an event near you or read *The Moisture Seekers* for more information. You can also attend a patient seminar or conference. Our National Patient Conference is scheduled for April 8th – 10th in San Francisco and is full of great speakers and topics. I hope you will consider attending.

Support the SSF

The SSF asks for support each year because without donors like you, the SSF will not be able to fund vital research needed to find the cause of Sjögren's as well as investigate new treatments for your disease. We appreciate the support, and this year, more than ever, it is critical that you help us raise enough funds to continue our research funding. With the economy already hurting many companies for 2010, it is individual support that will make the difference between what research we can fund and what research we have to turn away.

In this and future issues of *The Moisture Seekers*, you will be seeing a regular section called "I Stood Up…" where we will highlight patients who have answered our call to action and started to make a difference in their community. Take these ideas and make them your own! Together, with all of our voices combined, we will make a chorus so loud, everyone will know about Sjögren's!

Thanks for *Standing Up For Sjögren's!* ■

I Stood Up…

Tracey Bottiglia, Pennsylvania

Tracey Bottiglia, a daughter of a Sjögren's patient, decided to stand up and make a difference in her hometown. Together with her friends, Tracey helped to raise awareness and had fun at the same time. Here is Tracey's story…

"We held a Bake Sale to raise funds and awareness for the Sjögren's Syndrome Foundation. I decided to hold the bake sale at my church on election day while the polls were open. We began by asking the people of the church to donate baked goods. We also had crock-pot soups donated. In addition, we ordered sandwiches from a local supplier to sell. We also sold coffee, soda and water, and a local grocery store donated soup containers. I must say, the soups were a great seller!

I opened the church the night before the bake sale to collect items, package and price the food. I recruited about 15-20 people to donate items and the church helped by advertising the bake sale in advance. I also had volunteers who helped me work the sale during the day to help sell our items and also to distribute Sjögren's materials.

Overall, it was a great success! Not only did we raise awareness and educate our community about Sjögren's, we also raised funds for Sjögren's research!"

I hope you'll stand up and do something similar.

SSF Personal Support System

Listed below are SSF Contact Persons, members who volunteer to be sources of information for Sjögren's syndrome. Asterisks (*) indicate the location of where a SSF Support Group meeting is held.

International support groups are available throughout the world. Please contact our office for specific information.

ALABAMA

Daleville	Marilyn Murray*	(334) 598-5387
Dothan	Janis Monk*	(334) 691-2723
Montgomery	Sharon Miller*	(334) 277-2302

ALASKA

Palmer	Judy Masteller	(907) 376-6275
Seward	Sandra Mikat	(907) 224-5191

ARIZONA

Phoenix Area	Lois Peach*	(480) 391-2522

ARKANSAS

Conway	Betty Webster	(501) 329-6627
Little Rock	SSF Office*	(301) 530-4420
	or Lillie Major	(501) 227-0813
Sparkman	Laurine Langley	(870) 366-4388

CALIFORNIA

Felton/Santa Cruz	Shirley Stone*	(831) 335-2945
Fresno	Evelyn Bennett	(559) 436-8584
Glendale	Ricardina Astoquillca	(818) 241-8152
Hollister	Sharon West	(831) 634-0701
Inland Empire	Judy (Moffet) Whale*	(909) 624-1809
San Gabriel Valley	Susan Buller*	(909) 944-1773
Lakehead	Carol Sartain*	(530) 238-8031
Lemoore	Deborah Romerosa	(559) 925-1585
Long Beach	Kathy Bostrom*	(562) 595-8208
Los Angeles - West Hills	Rhoda Dennison*	(818) 346-6694
Oroville	Lynne Gould	(530) 589-1158
Riverside	Lynn Davis	(951) 681-8517
San Diego	Suzanne Davies*	ssfsuzannedavies@gmail.com
	Dona Frosio*	(619) 303-9004
San Francisco Bay Area	Nancy Crabbe*	(650) 593-9022
	Claire Goodman*	(925) 258-6666
San Rafael	Barbara Kinberger*	(415) 868-0171

COLORADO

Arvada	Susan Joyce	(303) 422-3864
Boulder Area	Dawna (Bunny) Swenson	(303) 652-2927
Colorado Springs	Andrea Shafer	(719) 487-1300
Denver Area	Carol A. Denewiler	(303) 755-9985
	Catherine F. Tomczak	(303) 751-5531
Denver/Englewood	Maurine Daniels*	(303) 721-0241
Evergreen	Lisa Torales	(303) 670-9296
		toralesl@msn.com
Ft. Collins/Loveland	Eunice Krivonak*	(970) 203-0147
Greenwood Village	Judy Kang*	(720) 488-7759
Littleton/Lakewood	Connie Walters	(303) 973-1878
Westminster	LaDonna Landry	(303) 426-5800

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DELAWARE

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Coral Gables	Georgene Slepin	(305) 446-4834
Coral Springs	Marrine Youngman	(954) 753-0939
Del Ray Beach	Jean Kaye	(561) 498-9364
Ft. Lauderdale	Georgie Littlefield*	(954) 977-0775
	Yvonne Sherrer, MD	(954) 229-7030
Jacksonville/Orange Park	Tana Still*	(904) 269-6871
Jacksonville	Kayleigh Porter	(904) 287-3052
Lady Lake	Karen M. Marshall*	(352) 259-1309
Miami Lakes	Beth Geyer	(305) 821-2453
N. Hutchinson Is.	Elizabeth Brinamen*	(772) 595-5873
Orlando/Lakeland	Joyce Tompkins*	(863) 701-0512
Tallahassee	Kay Tolworthy	(850) 877-5066
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Atlanta Area	Suzi Wixson*	(770) 642-0323
Dunwoody/Atlanta	Penny Hamond-Wolk	(770) 730-8550
McDonnough	Linda S. Davis	(770) 898-5837
Warner Robins	Irene Shue	(912) 929-3941

IDAHO

Potlatch	Patty Gilbert	(208) 875-1590

ILLINOIS

Arlington Heights	Diana Bonadonna	(847) 398-0407
Bloomington	Joyce Kaye	(309) 663-0564
Chicago Area	Heidi Shierry*	(630) 279-9437
		or (630) 853-6836
Fox Lake	Mary Ann Guisinger	(847) 629-5559
Liberty	Mary Ann Graham	(217) 645-3497
Plainfield	Audrey M. Grey-Lowry*	(815) 436-5168
	April Flentge*	(815) 886-4715
Urbana	Waneta Mehaffey	(217) 367-8161

INDIANA

Indianapolis	Diana Altom*	(317) 356-3243
South Bend	Sarah Reichert *	(574) 342-2285

IOWA

Des Moines	Suzanne Sullivan	(515) 537-1345
Dubuque	Shirley White*	(563) 583-6795
Wilton	Connie I. Brown	(563) 732-2420

KANSAS

Lenexa	Janet Nichols*	(913) 492-9581

KENTUCKY

Lexington	Jack Wood	(606) 277-8123
Louisville	Debra L. Henning	(502) 231-9130
	Karen M. Solomon	(502) 245-3120
Rineyville	Jisun Mudd	(270) 877-7729

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LOUISIANA

Baton Rouge	Debbie Fuselier	(225) 928-4341
Kaplan/Lafayette	Tanya Broussard*	(337) 643-3565
New Orleans	Connie Benton	(504) 488-6977
New Orleans	Lynn Weinberg	(504) 895-2595
Pineville	Mary Maddox	(318) 445-7448

MAINE

Alfred	Elizabeth Hayes	(207) 324-9654

MARYLAND

Bel Air	Eva L. Plude*	(410) 836-1040 or bigeva@qis.net
Frederick	Elizabeth E. Ward*	(301) 663-3947
Montgomery County Area	Bonnie Schneider*	(301) 774-4662
Prince George's & Southern Maryland	Ruth White*	(301) 246-4476

MASSACHUSETTS

Boston Area	Lynn C. Epstein, MD*	(617) 636-3932
E. Long Meadow	Janet Young	(413) 525-8211
Plymouth Area	Joanne Levy	(508) 224-2262
Springfield	Kitty Berger	(413) 786-6552
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South Grafton	Gerry Lauria	(508) 839-4095

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Grand Rapids	Ruth Keur*	(616) 453-8510
Grosse Pte Farms	Mary Lapish	(313) 885-7523
Jackson	Charlene Pung*	(517) 788-9824
Lansing	Laura Hall	(517) 887-6663
Livonia	Charlotte Pumo	(734) 427-8335
Presque Isle	Rosemary Kause	(517) 595-3288
St. Clair	Bonnie Wright	(810) 329-9241
Stanwood	Karen M. Marshall	(231) 972-3110
Sturgis	Marcia L. Arend	(269) 651-6798

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Sjögren's Society of Canada

Contact: Lee Durdon, President
Tel: (888) 558-0950 (voicemail)
Web site: www.sjogrenscanada.org
E-mail: info@sjogrenscanada.org

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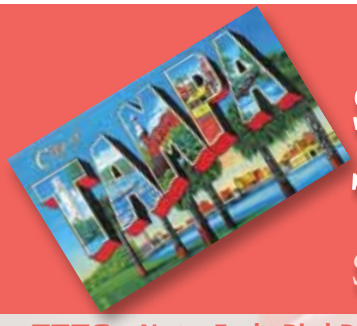
Q *I hear that in China some Sjögren's patients are being managed with traditional Chinese herbs. How effective are they?*

A Some Chinese Sjögren's patients are managed with Chinese herbs, either alone or in combination with Western Medicine (e.g. steroids, hydroxychloroquine). In particular, Tripterygium wilfordii (thundergod vine) and Radix Paenoiae (white peony root) have been used effectively to help manage Sjögren's. White peony root, a member of the Ranunculaceae family, is generally used for patients with milder disease. Thundergod vine, a member of the Celastraceae family, is generally used for patients with moderate to severe disease.

Neither of these herbs has been well studied in the Sjögren's population. Their use in China is based on clinical experience. Importantly, both of these herbs have potential toxicities and must be used with caution. In particular, thundergod vine can potentially cause low white blood cell counts, low platelets, and cessation of the menstrual cycle.

continued page 13 ▼



Sjögren's Syndrome Foundation
TAMPA PATIENT SEMINAR
SATURDAY, FEBRUARY 20, 2010

FEES – Note: Early Bird Deadline is February 1, 2010

	February 1st and before	February 2nd and after
SSF Members & Guests	$65 per person	$85 per person
Non-Members	$90 (includes one-year membership)	$110 (includes one-year membership)

- *A fee of $25 will be charged for all seminar registration cancellations. Refund requests must be made by February 1, 2010. After that date, we are sorry but no refunds will 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 (800-475-6473 ext. 210) by February 12th.*
- *A limited number of rooms are available at the Tampa Westshore Marriott, 1001 North Westshore Boulevard, Tampa, Florida 33607, at the SSF rate of $119 per night plus tax if reservations are made by January 26, 2010. Call the toll-free hotel reservation number at 800-228-9290 or call the hotel direct at 813-287-2555 and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.*

Call Today
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"Surprises from CD" continued from page 5 ▼

implied that avoiding gluten during the first year of life might essentially train that developing immune system to tolerate gluten thereafter, as healthy people do, rather than being overstimulated by it. So far we have enrolled more than 700 potentially genetically susceptible infants in this study, and preliminary findings suggest that delaying gluten exposure reduces by fourfold the likelihood that CD will develop. It will be decades, however, until we know for certain whether this strategy can stop the disease from ever occurring.

Given the apparently shared underpinning of autoimmune disorders in general, researchers who investigate those conditions are eager to learn whether some therapeutic strategies for CD might also ease other autoimmune conditions that currently lack good treatments. And with several different approaches in the pipeline to treat CD, we can begin to hope that this disease, which has followed humanity from the dawn of civilization, is facing its last century on earth.

Alessio Fasano is professor of pediatrics, medicine and physiology and director of the Mucosal Biology Research Center and the Center for Celiac Research at the University of Maryland School of Medicine. Much of his basic and clinical research focuses on the role of intestinal permeability in the development of celiac disease and other autoimmune disorders.

Treatment Ideas

Today, patients with celiac disease have one therapeutic option: avoid all foods that contain gluten. But because following a restricted diet can be difficult, investigators are exploring other options for patients, such as those listed below. These are early days in the process; no drug in the table has yet reached the advanced clinical trials needed to gain marketing approval. ■

Therapy	*Drug Name (Investigator/Status)*
Avoid gluten in the diet of infants through their first year of life	No drug (University of Maryland and, separately, Marche Politechnic University, Italy/in human trials)
Degrade otherwise indigestible gluten fragments, so they cannot evoke an immune response	ALV003 (Alvine and, separately, ANPEP at VU University Medical Center, the Netherlands/in human trials)
Block zonulin from making the gut permeable	Larazotide (Alba Therapeutics/in human trials)
Keep tissue transglutaminase from modifying gluten fragments in ways that stimulate the immune system	No name (Numerate and Stanford University/under study in the laboratory)
Stop HLA-DQ2 from attaching to gluten peptides and displaying them to helper T cells	Mimics of gluten (Leiden University, the Netherlands, and, separately, Stanford University/under study in the laboratory)
Vaccinate patients with selected gluten fragments to induce helper T cells to tolerate, rather than react to, gluten displayed by HLA-DQ2 molecules.	Nexvax2 (Nexpep, Australia/in human trials)
Block migration of killer T cells into the intestinal lining	CCX282-B (Chemocentryx/in human trials)
Start a hookworm infection (the parasites dampen a host's immune responses in the gut)	Hookworm parasites (Princess Alexandra Hospital, Australia, and collaborators/in human trials)

in memoriam

In Memory of David Nelson
Lois & Andrew Anderson
Donald & Beverly Brostrom
Kenneth G. Craven
Laura M. Daumann
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In Memory of Ruth K. Ohl
John & Lisa Fitzell

in honor

In Honor of Dr. Steven Carson's Birthday
Lynn-Anne & Stuart Spitzer

In Honor of Jenny Kindle's Birthday
Danielle Miller

In Honor of JoAnne Levy's Wedding
Jaisa & Sheera Olasky

Merry Christmas to Carol J. Gerrish
Lauren Gerrish

In Honor of Virginia Sue Kelly
Susan Mactye

"Information You Requested" continued from page 11 ▼

Thundergod vine and white peony root are both approved by the Chinese State Food & Drug Administration. As such, these herbs are sold as chemical extracts and dispensed in pill form. Their production is monitored under strict safety regulations so that each pill has a standard amount of active ingredients and minimal amount of toxicity. This stands in contrast to the situation in the United States where most Chinese herbs are sold in whole dried form, brewed in boiling water, and then taken as a liquid. No guarantee can be made about the amount of active ingredients or toxicity in each liquid concoction.

At this time, these herbs are not being used to treat Sjögren's patients in the United States. They are not approved by the U.S. Food & Drug Administration. Though these herbs may be available for purchase, they are not inspected for quality and purity, which is concerning for potential toxicity associated with impure herbs. Furthermore, these herbs are not available as chemical extracts in the U.S. so no guarantee can be made about the amount of active ingredient or toxicity in the herbs.

Aileen Chang

Third-Year Medical Student, University of Pennsylvania School of Medicine

2008 Sjögren's Syndrome Foundation Student Fellowship Recipient

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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 now there is a wonderful opportunity to Empower Yourself and take more 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 2010 SSF National Patient Conference in San Francisco, California.

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. Presentation topics will include:

- Overview of Sjögren's Syndrome
- CNS Disease in Sjögren's
- Lung Complications
- Dry Eye and Dry Mouth Issues
- Neuropathy in Sjögren's
- Sjögren's Survival: A Patient Perspective
- The Doctor/Patient Relationship
- Nutrition and Sjögren's
- Heart Disease: The Impact of Inflammation & Autoimmune Diseases

*So this April 9-10, we invite you to come to San Francisco, California, and experience a weekend to **Empower Yourself** as you gain knowledge and heighten your understanding of Sjögren's at the 2010 National Patient Conference!*

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APRIL 9–10, 2010

1 ATTENDEE – complete for each registrant

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Attendee Name(s) _____

Street Address _____

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2 FEES – please circle appropriate fee(s) (Note: Early Bird Deadline is March 15, 2010)

	March 15th and before	March 16th and after
SSF Members & Guests	$165 per person	$185 per person
Non-Members	$190 per person	$210 per person
TOTAL:		

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- *Refund requests must be made in writing. Registrants whose written request is received by* ***March 26, 2010*** *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 (800-475-6473 ext. 210) by March 26th.*
- *A limited number of rooms are available at the San Francisco Airport Marriott (1800 Bayshore Highway, Burlingame, California 94010) at the SSF rate of* ***$129 per night plus tax*** *if reservations are made by* ***March 15, 2010****. Call the* ***toll-free*** *hotel reservation number at 800-228-9290 or call the San Francisco Airport Marriott directly at 650-692-9100 and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.*
- *The San Francisco Airport Marriott provides a complimentary shuttle service to/from the San Francisco International Airport.*

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We are looking for 20 inspired individuals to join us as we begin to train for this challenge. We understand that not all Sjögren's patients are able to participate in a marathon, so we hope you will extend this invitation to family members as well as friends who may be interested in participating in this challenge!

To sign up, contact Elyse Jordan directly at (800) 475-6473 ext. 217 or ejordan@sjogrens.org