

# The Sjögren's Syndrome Foundation Moisture Seekers



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 SjogrensSyndromeFoundation

 @MoistureSeekers

## Childhood Sjögren's: A Guide for Parents and Doctors

by Scott M. Lieberman, MD, PhD and Jay J. Mehta, MD, MS

Sjögren's is a complex autoimmune disease in which one's own immune system attacks one's own tear-producing (lacrimal) and saliva-producing (salivary) glands. This results in the development of profound eye and mouth dryness with potential for vision-threatening damage to the eyes, poor oral health, and difficulty swallowing. Sjögren's may also affect other organs, and in some individuals the disease may progress to cancer development (typically lymphoma). Sjögren's is most commonly diagnosed in adult women in their 40's and 50's, typically presenting with symptoms of dry eyes and dry mouth; however, the autoimmune process begins years (likely decades) before these symptoms are evident and diagnosis is made. In fact, many adults with Sjögren's recall symptoms dating back to childhood or early adulthood. Thus, childhood Sjögren's may be viewed as an earlier state of autoimmunity compared to the later stage of adult Sjögren's rather than a distinct entity, though formal evidence to suggest this is lacking. It should not then be surprising that childhood Sjögren's most often presents differently than adult Sjögren's with symptoms of dryness being less prominent. Here, we will discuss aspects of childhood Sjögren's including when it should be suspected by parents and clinicians, how it is diagnosed, clinical manifestations (what parts of the body may be affected), and key aspects of management. It is important to note that very little is known about the long-term prognosis or consequences of childhood Sjögren's. This is due at least in part to the difficulties in diagnosing it early on. To remedy this, we have recently organized a group of pediatric rheumatologists from around the world (Childhood Sjögren's Workgroup) to better define and better understand childhood Sjögren's.

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## The Time is Now for Sjögren's!

by Elizabeth Trocchio  
SSF Director of Marketing

Four years ago Steven Taylor, the Sjögren's Syndrome Foundation (SSF) CEO, said, "It will take an army to achieve our 5-year *Breakthrough Goal*: but just imagine if we all band together – how we could change the face of Sjögren's for all patients, present and future!"

And in 2015, that army of volunteers started to make incredible strides in areas of awareness, education and research! Our volunteers continue to fight for all those who suffer from this debilitating disease.

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e-mail: [tms@sjogrens.org](mailto:tms@sjogrens.org)  
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## When Should Sjögren's be Suspected in a Child?

### Salivary Gland Swelling

The single most common presenting feature of childhood Sjögren's is swelling of the parotid gland(s) – the major salivary gland(s) located over the angle of the jaw on both sides. Swelling of these glands, either on one side of the face or both, is typically accompanied by tenderness in the affected area. Symptoms may be worse after eating. Some children will have a fever and seem overall unwell when this occurs, but some children will have symptoms localized only to the affected gland(s). Importantly, Sjögren's is not the only thing that causes swelling of the parotid glands. So, the first time this occurs, your child's doctor may want to treat with antibiotics as bacterial infections may cause similar symptoms especially accompanied by fever. Viral infections (such as mumps, for example) can also cause similar swelling. The presence of stones in the parotid duct (the tube through which saliva travels to get from the gland to the oral cavity) may cause similar symptoms but will usually not occur on both sides of the face. It is rare that consideration of Sjögren's is made at the time of the first episode of parotid gland swelling. If symptoms do not improve over time (typically within 1-2 weeks) or if they occur repeatedly over time, consideration for Sjögren's should be made so appropriate testing can be done.

### Dry Eyes, Dry Mouth And Beyond

Sjögren's should be considered in any child with oral or ocular manifestations suggesting decreased saliva and/or tear production including not only symptoms of dry mouth or dry eyes but also multiple recurrent dental cavities despite adequate oral hygiene, the need to take frequent drinks to help swallow dry foods, or a sensation of grittiness in the child's eyes necessitating the frequent use of rewetting drops. While these features may be caused by multiple different conditions, Sjögren's should be considered in any child with these symptoms. Specifically asking your child's dentist or eye doctor if they seem to have decreased saliva and/or tears may help to prompt a referral to a pediatric rheumatologist to evaluate for Sjögren's.

### Joint Manifestations

Joint pain (arthralgia) or joint inflammation (arthritis) may occur in children with Sjögren's and may be the initial manifestation. If your child has stiff joints in the morning that loosen up over 30+ minutes, or joint swelling or warmth on a regular basis, your child should be evaluated by a pediatric rheumatologist to determine if they have inflammatory arthritis. This may be a presenting feature of childhood Sjögren's; however, other childhood rheumatic diseases such as juvenile arthritis are more common

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and will also be considered by the pediatric rheumatologist. Because joint pain without inflammation (arthralgias) is not specific, clinicians must have a high index of suspicion to consider Sjögren's as the possible cause. If this occurs on a regular basis or is accompanied by other vague symptoms you should discuss with your child's regular healthcare provider whether a pediatric rheumatology referral is warranted.

### *Other Manifestations*

Any child with inflammation of kidneys, lungs, brain or spinal cord, or with autoimmune manifestations affecting the blood should be evaluated by the appropriate specialist(s). If another clear cause is not ascertained, consideration for Sjögren's should be made because childhood Sjögren's can begin by affecting almost any part of the body. Similarly, any child with vague symptoms including prolonged or recurrent fevers, enlarged lymph nodes, or certain rashes should be evaluated for the possibility of Sjögren's as the underlying cause.

### *How is Childhood Sjögren's Diagnosed?*

When Sjögren's is suspected in a child (typically by a pediatric rheumatologist), a series of tests are performed to help determine if this is the diagnosis. Though these tests are similar to those used in adults, child-specific normal values have not been clearly defined for many of these tests making diagnosis of childhood Sjögren's a bit more complicated.

#### *Tests include:*

- 1) Blood tests looking for evidence of:
  - a) Autoimmunity (antibodies such as antinuclear antibody, anti-SSA, anti-SSB, rheumatoid factor)
  - b) Inflammation (erythrocyte sedimentation rate, C-reactive protein, immunoglobulin G levels)
  - c) Damage to the salivary glands (amylase) or other organs (liver enzymes, kidney/urine tests)
- 2) Imaging studies to evaluate for evidence of damage to salivary glands or other organs (ultrasound, magnetic resonance imaging, or other modalities).
- 3) Biopsy of minor salivary glands in the inner lower lip or, rarely, of other salivary glands, lacrimal glands, or other affected organs.

Evaluation by other health care providers should be performed, specifically to include an ophthalmol-

ogist (eye doctor) to evaluate for evidence of dry eye by measuring tears (Schirmer test) or damage to the cornea (ocular staining) and a dentist or oral surgeon to evaluate for evidence of decreased saliva and dental abnormalities. Specific measurements of saliva are not typically done in children but would include measuring whole saliva, salivary pH, or special imaging such as salivary sialography. If other organs are involved, additional specialists may be involved in your child's care.

Once these tests are performed and results are evaluated, a diagnosis of childhood Sjögren's may be made. Efforts are currently underway to determine which combinations of tests should be considered sufficient for the diagnosis of childhood Sjögren's, but both blood tests and minor salivary gland (lip) biopsy results are often key to making the diagnosis.

### *What other manifestations of Sjögren's may occur?*

Any of the organs mentioned above as being affected at the time of diagnosis may also become affected later on during the course of the disease. Sjögren's is a chronic condition that currently has no cure. Thus, lifelong monitoring by the appropriate health care providers is vital to assuring the best possible management of affected organs/disease manifestations. Notably, some of the manifestations mentioned below are not common but are serious complications worth noting.

#### *Salivary and Lacrimal Gland Manifestations*

As noted above, salivary gland swelling is commonly present at or before the time childhood Sjögren's is diagnosed. Even in children who do not present in this way, parotid gland swelling may occur. Similarly, over time, children with Sjögren's may develop dry mouth and dry eye symptoms typical for adult Sjögren's, but whether these are likely to occur during childhood versus later on in adulthood is not known.

#### *Skin Manifestations*

Rashes may occur and may be the first sign of childhood Sjögren's. These may be due to inflammation of the small blood vessels in the skin (cutaneous vasculitis). Sometimes the rash appears similar to that seen in lupus. Color changes of the fingers in response to cold stimuli (weather, cold beverages, cold swimming pool) or stress, known as Raynaud phenomenon, may occur in children with Sjögren's. In some cases this may result in extreme compromise of blood flow to the tips of the fingers, toes, and nose that can result in tissue damage if prolonged.

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## You Stood Up!

*Thank you to the SSF Luncheon Speakers at the 2015 American College of Rheumatology Conference!*

At the recent American College of Rheumatology conference in San Francisco, the Sjögren's Syndrome Foundation held their annual luncheon meeting to discuss Sjögren's. This luncheon is attended by key Sjögren's rheumatologists, researchers and specialists from around the world.

This year's topic, "Expanding our Clinical View of Sjögren's" brought together an expert panel to provide a diverse perspective on Sjögren's. This panel included specialists from pediatrics, gynecology/urology and neurogastroenterology. Each presenter offered a unique clinical perspective on Sjögren's, what they see in their specialties and how rheumatologists can not only help identify certain manifestations and refer earlier to specialists, but also how the specialists generally treat the specific manifestations they see.

Scott M Lieberman, MD, PhD, a pediatric rheumatologist from Carver College of Medicine at the University of Iowa who co-authored the lead article in this issue of *The Moisture Seekers*, spoke to the group about the incidence of pediatric Sjögren's. Dr. Lieberman stressed that Sjögren's is seen in children and that often times the symptom patterns are different than those seen in adults. In fact, a recent study found that the most common symptom they saw in children was Parotitis.

The Effect of Sjögren's on Gastrointestinal (GI) Motility was discussed by Mimi S. Lin, MD, Director of Neurogastroenterology & Motility Education Center for Neurogastroenterology & Motility at California Pacific Medical Center. Dr. Lin's presentation gave attendees a clearer understanding of the different effects Sjögren's may

have on the digestive system from esophagus through the large intestines. Different treatments for GI issues were discussed.

Lastly, Rita Melkonian MD, FACOG from Marin General Hospital shared the urogynecological aspects of Sjögren's. The topic of vaginal dryness, its potential severity and current treatment were discussed. Dr. Melkonian also covered the effects of Sjögren's on the urinary tract and bladder, as well as, obstetrical considerations for mother and baby when a Sjögren's patient becomes pregnant.

We thank these specialists for standing up and joining us at the luncheon to share their distinct experiences and knowledge with the world's leading Sjögren's experts! ■



*SSF ACR Luncheon Today's speakers from left to right- Steven Taylor (SSF CEO), Dr. Rita Melkonian, Dr. Mimi Lin, Dr. Scott Lieberman, Dr. Nancy Carteron (Chair of the SSF Medical & Scientific Advisory Board)*

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### *Blood Manifestations*

Autoimmune attack on any type of blood cells may occur in Sjögren's resulting in decrease in red blood cells (anemia), white blood cells (leukopenia), or platelets (thrombocytopenia). These may occur without any symptoms, but as anemia progresses children may become pale and fatigued; as leukopenia progresses children are at risk for developing infections; and as platelets decrease, easy bruising or bleeding may occur.

### *Kidney Manifestations*

Sjögren's may affect the kidneys leading to multiple possible manifestations. Inflammation in the kidneys is typically tubulointerstitial nephritis – inflammation affecting the tubules in the kidneys (as opposed to glomerulonephritis – inflammation affecting the filtration apparatus known as the glomerulus); however, either can occur. The manifestations of kidney inflammation include abnormalities detected on urine analysis including protein in the urine, blood in the urine, calcium deposits in the kidneys (nephrocalcinosis), or renal tubular acidosis (alterations in the ability of the kidney to secrete protons into the urine resulting in the blood being acidotic, i.e. having a low pH due to increased protons present). A special note regarding the latter – when the kidney fails to secrete protons in the case of renal tubular acidosis it tends to secrete potassium instead, which may result in low potassium (hypokalemia) that may progress to the point of paralysis due to extremely low potassium in the blood (hypokalemic paralysis). This is a medical emergency.

### *Nervous System (brain, spinal cord, nerves) Manifestations*

Children with Sjögren's may develop an autoimmune attack on a water channel in the brain and spinal cord called aquaporin 4. This results in inflammation of the optic nerve (the nerve that connects the eye to the brain) and the spinal cord that may manifest as blindness and paralysis and is a medical emergency. This condition is called neuromyelitis optica. While it may occur on its own in people without Sjögren's, in any child with neuromyelitis optica the possibility of Sjögren's should be considered. Treatments are available to halt the inflammation and reverse the damage so that children with neuromyelitis optica may have little/no permanent vision loss or paralysis, though recurrences are possible. In some children, a blood test can help determine if this process is going on. Inflammation of peripheral nerves

manifested as numbness, tingling, pain, or weakness may occur but is less common in children.

### *Lung Manifestations*

Sjögren's may affect the lungs, including inflammation and pulmonary hypertension (increased blood pressure in the arteries within the lungs), though these manifestations are less common in children than in adults with Sjögren's.

## **How is Childhood Sjögren's Treated and Managed?**

Management of children with Sjögren's is dictated by the specific manifestations of their disease. Regardless of specific organs affected, vigilant and regular care by oral and eye health care providers are absolutely necessary for maximizing oral and ocular health. For example, regular dentist visits to help maintain teeth in the face of potential decrease in saliva is important. Your child's dentist may want to apply regular fluoride treatments to help protect his/her teeth from development of cavities, a risk of which is increased if your child does not make adequate saliva due to Sjögren's. Similarly, ophthalmologists will help monitor for and manage dry eye symptoms, which may include simple rewetting drops or may include anti-inflammatory drops. If children have dry mouth or dry eye symptoms, additional medications that stimulate saliva and tear production may be used. Other measures for dry mouth and dry eye symptoms include the use of sour candies that stimulate saliva, oral lubricating gels, saline rewetting eye drops, and anti-inflammatory eye drops.

A short course of oral corticosteroids (such as prednisone) may help to improve symptoms in the short-term but additional therapy should be used to prevent long-term exposure to high doses of these medications. Typically, children with recurrent parotid gland swelling are treated with daily oral medications such as hydroxychloroquine (an anti-malarial antibiotic that has anti-inflammatory properties), which often helps minimize the episodes of recurrent parotid swelling. In our experience, hydroxychloroquine is also helpful with improving the fatigue and arthralgias commonly seen in children with Sjögren's.

More potent immunosuppressive medications commonly used for other rheumatic diseases (including methotrexate, mycophenolate mofetil, azathioprine, rituximab, belimumab, abatacept) may be used especially if children have other organ involvement

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# SSF Personal Support System

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

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Decatur Candace Burnham\* (256) 476-7134

## ALASKA

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

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Lois Peach (480) 391-2522

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Lemoore Deborah Romerosa (559) 925-1585  
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Oroville Lynne Gould (530) 589-1158  
Paso Robles Cathy Sawyer (805) 286-4649  
San Diego Suzanne Davies\* sfsuzannedavies@gmail.com (619) 461-0725  
Dona Frosio\* (650) 593-9022  
San Francisco Bay Area Nancy Crabbe\*

## CALIFORNIA (continued)

South San Francisco Thelma Dito (650) 589-5950  
San Jose Debra Ashford\* (408) 708-6015  
Santa Rosa Laura Strom\* (707) 889-9168

## COLORADO

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Maurine Daniels\* (303) 721-0241  
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Denver Area Eunice Krivonak\* (970) 203-0147  
Ft. Collins/Loveland Connie Walters (303) 973-1878  
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Coral Gables Georgene Slepín (305) 446-4834  
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Jacksonville Penny Oliver (904) 535-9366  
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Tana Still (904) 269-6871  
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N. Hutchinson Is. Elizabeth Brinamen (772) 595-5873  
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Sarasota Lorraine Murray (941) 922-1379  
Tampa/Clearwater Michelle Wallace\* (727) 791-0002  
West Palm Beach Janet Young (561) 283-1670

## GEORGIA

Athens Area Terry Rundorff\* (706) 769-8461  
Dorothy Wade\* (706) 769-9795  
Atlanta Area Suzi Wixson\* (770) 642-0323

## HAWAII

Ewa Beach Melaca Cannella\* [alwaysbhealthynhappy@gmail.com](mailto:alwaysbhealthynhappy@gmail.com)

## IDAHO

Boise Richard Bliss\* (208) 816-3686  
Kathy Ellis\* (208) 921-0613  
Patt Gilbert (208) 875-1590

## ILLINOIS

Arlington Heights Diana Bonadonna (847) 398-0407  
Chicago Area Heidi Shierr\* (630) 853-6836  
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Indianapolis	Diana Altom*	daltom50@gmail.com (317) 408-2844
Newburgh	Vivian Kistler*	(812) 490-6580
	Sally Dekarske*	

## IOWA

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

## KANSAS

Lenexa/ Overland Park	Janine Bensman*	(913) 897-2441
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Louisville	Debra L. Henning	(502) 231-9130
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## LOUISIANA

Baton Rouge	Carolyn S. Lee	(225) 262-1060
Lafayette	Peggy Garrett	(337) 234-4937
New Orleans	Lynn Weinberg	(504) 895-2595

## MAINE

Alfred	Elizabeth Hayes	(207) 324-9654
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Lansing	Laura Hall	(517) 887-6663
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

## MINNESOTA

Eden Prairie	Julie Ermer	(952) 943-9546
Maplewood	Phyllis Peterson	(651) 778-8035
Minneapolis	Cynthia Neubecker*	(612) 729-5616
St. Louis Park	Bette Tobin	(952) 920-2941
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## MISSISSIPPI

Biloxi	Della Mc Caughan	(228) 432-7748
Tupelo	Holly W. Bullock	(662) 844-2877

## MISSOURI

St. Joseph	Leona Stevens	(816) 364-3453
St. Louis	Danni Dugger*	(314) 662-0585
	Janie Norberg	(314) 521-4663
	Jane Rombach FSM	(314) 776-5764

## MONTANA

Big Arm/Kalispell	Tedi Schilling*	(406) 849-5537
Billings	Helen Armstrong	(406) 245-0549
Bozeman	Betty Dilbeck	(406) 582-1933
Polson	Tedi Schilling*	(406) 849-5537

## NEBRASKA

Lincoln	Jolene John-Beckstrom*	(402) 217-0600
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## NEW HAMPSHIRE

Newington	Teresa Callahan*	(603) 493-1463
Nottingham	Carol Markee	(603) 895-4812

## NEW JERSEY

Central/Southern	Ann Kiessling*	(732) 996-7952
Edgewater	Joanna Fabian	(201) 886-0805
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Teaneck	Nan Lehmann	(201) 836-4239

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Albuquerque	Shawn CDeBaca*	(505) 898-5620
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Northeast Ohio	Mary McNeil*	(330) 342-7870
Toledo Area	Judi Furlong, MD*	(419) 824-1927

## OKLAHOMA

Edmond	Sharon Abrams*	(405) 330-2356
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## OREGON

Baker City	Susan Castles	(541) 523-3323
Bend	Angie Siefer	(541) 318-4751
Canby/Portland	Linda Shields*	(503) 266-3680
Medford	Jane Finley	(541) 770-6558

## PENNSYLVANIA

Bethlehem	Rebecca Ridgick	(610) 865-4795
Clarks Summit	Judy Rienzi	(570) 586-6635
Easton	Janet Kirk	(610) 253-9324
Harrisburg	Kathy Boyd*	(717) 737-3890
Montgomery	Kathy Gilchrist	(610) 933-0843
Mount Carmel	Orinda Ford	(570) 339-2223
Philadelphia	Kathi Borden *	(610) 384-8723
	Sandra Pacini (Phone Contact)	(215) 672-2983
	Barb Barbon	(610) 775-7949
	Sandy Burkett*	(412) 220-8180
	Pamela Ebaugh	(412) 732-0635
	Sheila Rae Lytle	(724) 961-3525
	Jane Potteiger	(412) 922-9826
Pittsburgh Area		

**PENNSYLVANIA** (continued)

Scranton Linda Rosengrant-Lohrey (570) 885-0141  
 Wallingford Ruth Goldman (610) 441-1441

**RHODE ISLAND**

North Smithfield Lynne Messina (401) 766-8645  
 Warwick Joyce Bert (401) 738-0857

**SOUTH CAROLINA**

Greenville Debbie Brown\* (302) 419-6565

**SOUTH DAKOTA**

Beresford Sue Christensen (605) 563-2483

**TENNESSEE**

Memphis Betty Wetter (901) 682-2073  
 Nashville Vicki Baldwin\* (615) 243-4560  
 Nancy Hoesel (615) 332-7443

**TEXAS**

Austin/Georgetown Linda Frost\* (512) 255-6049  
 Helen Smith\* (512) 869-8840  
 Bedford Audra Johnson (817) 498-6552  
 Dallas Cathy Ingels\* (972) 948-8606  
 El Paso Michael Najera, DDS (915) 833-3330  
 Harlingen Barbara Ann Purdy (956) 423-3192  
 Houston Shani Corbiere sjogrens@att.net  
 Lubbock Jo Murdock (806) 792-9862  
 Montgomery Wanda Coleman (936) 448-4325  
 Nacogdoches Sidney Fowler, DDS (936) 564-9401  
 Richardson Kay Turner (972) 235-8521  
 Roanoke Area Shirley Stone\* (682) 502-4910  
 Tyler Laura Moran, RN (903) 534-9131  
 The Woodlands Marilyn Adams\* (281) 298-9196

**UTAH**

Salt Lake City Dr. Kathie Coopersmith\* (801) 476-9701  
 kathie.coopersmith@gmail.com  
 Linda Phillips\* (801) 544-9603

**VIRGINIA**

Dinwiddie Denise Rainey (804) 469-7505  
 Harrisonburg/ Shenandoah Valley Teresa C. May\* (540) 433-5638  
 Lynchburg Ida B. Powell (434) 386-3428  
 Marion Debra L. Hall (276) 646-3023  
 Mount Jackson/ N. Shenandoah Valley Robert & Jane Perry\* (540) 477-2088  
 New Bern Robert E. Wallace (540) 674-2922  
 Norfolk/ Hampton Roads Bonnie Elverum\* (757) 268-4928  
 Northern Virginia SSF National Office\* (301) 530-4420  
 Salem Carol Watson, RN\* (540) 389-7503

**WASHINGTON**

Bellingham Linda Hughes (360) 676-1926  
 Betty Willert (360) 312-1597  
 Federal Way/Seattle Karen Schlaht (253) 815-8937  
 Pasco Joretta Heath (509) 547-3832  
 Spokane Jaqueline Riley (509) 466-2432  
 Tacoma/Spanaway Judy Kay Reynolds (253) 531-7369

**WEST VIRGINIA**

Moundsville Pat Kleinedler (304) 845-8473

**WISCONSIN**

Brookfield Carole Oldenburg (262) 786-3858  
 Madison Nancy Johnson\* (608) 332-5928  
 Milwaukee Area Wendy Liedtke (414) 541-5857  
 Shelley Olson\* (414) 659-7179  
 River Falls Mimi Trudeau (715) 425-8183

If you need to find out about a support group in Canada or outside the United States, please contact the SSF at (301) 530-4420

 **in memoriam**

**In Memory of Doris Aragon**

Christina Molina

**In Memory of Iris Cohn**

Alexi and Anthony Giallanzo Doris Prussian  
 Joni and Steve Shapiro

**In Memory of Mary Conron**

WorldStrides Family Rich and MaryAnn Regiec  
 Bob Whelan Randall and Catherine Brown  
 Kate and Family  
 Rosewood Village Hollymead Assisted Living, LLC

**In Memory of Irene Greene**

Shannon Mitchell

**In Memory of Jessica Jacobson-Irato**

Jennifer and Alan Falcone George and Dee Hockett  
 Jan and Tom Smay Rich Urness

Michael Norlin

**In Memory of Phyllis Jager**

Margaret Cochran

**In Memory of Janet Knox**

Katie Gorham

**In Memory of Barbara Kurz**

Marty Darocha

**In Memory of Mildred Neucere Rieder**

Thomas Randolph (Randy) Richardson and Lisa Gourgues  
 Evans and Eileen Neucere  
 Stennis Space Center/Engineering and Test Directorate

**In Memory of Marianne Pierson**

Lester and Barbara Albert William and Candy Norder  
 Maxine and Douglas Shoemaker

**In Memory of Anita Regnier**

Ron and Jan Stadtherr

 **in honor**

**In Honor of Ken and Anne Economou**

Bob and Debbie Rosenfeld

**In Honor of Carol Gerrish**

Lauren Gerrish

**In Honor of Robin and Kevin Green**

Barbara and Alan Levin

**In Honor of Laura Martinelli**

Sharon Garroway

**In Honor of Margaret Mondlak**

Steve Mondlak

**In Honor of John Pupo**

Eunkyong Yi

**In Honor of Jennifer Rutschow**

Dale Rutschow

**In Honor of Heidi Shiery**

Paula and Ed Josephson

**In Honor of Scott Spencer**

Harry Spencer

**In Honor of Lauren Teukolsky**

Saul and Roselyn Teukolsky

**In Honor of Chris, Teri, and Dakota**

Dave, Ann, Ethan, and Sara Makulec

**In Honor of Friends at Elle Salon**

Debbie Herman

**In Honor of Julie Gross and Brandon Cohen**

Margaret and Andrew Vogelson

*"Children and Sjögren's" continued from page 6 ▼*

– including brain and spinal cord, lungs, joints, blood, etc. Newer medications are continually being studied for use in adults with Sjögren's, but no specific medication seems to be superior in managing all features of Sjögren's in adults, and no studies of immunomodulating therapies have been performed in children with Sjögren's.

## Prognosis

Because of the general lack of suspicion for diagnosing childhood Sjögren's among most clinicians, coupled with a lack of a clear set of criteria appropriate for use in diagnosing childhood Sjögren's, we do not have any data on long-term outcomes. Some anecdotal evidence suggests that while children may not have the typical dry eyes and dry mouth symptoms that adults have, they are likely to develop these symptoms over time. One key question is whether any specific treatments given early on will prevent progression of disease manifestations, but this will not become evident for quite some time as we are at only the initial stages of defining this disease in children. Similarly, whether we can predict which organs will become involved/affected over time remains to be determined. Considerable work has been done to determine key risk factors for morbidity and mortality in adults with Sjögren's, including identifying the features (clinical, laboratory, and histopathology) that suggest higher risk of developing cancer (especially lymphoma) over time. Once we define childhood Sjögren's, we will be able to evaluate these features to determine if they are applicable to children as well.

## Take Home Message

Sjögren's occurs in children but it is likely under diagnosed due to lack of the typical symptoms of dry eyes and dry mouth that are prominent in adults with Sjögren's. An increased awareness of the possibility of childhood Sjögren's will help increase early diagnosis. Any child with dry eyes, dry mouth, or recurrent or persistent salivary gland swelling should be evaluated by a pediatric rheumatologist to determine if he/she has childhood Sjögren's. In addition, any child with unexplained fevers or inflammation affecting any organ without another clear cause should be evaluated for possible Sjögren's. Once diagnosed, maintaining regular visits with multiple healthcare providers is key to maximizing effective management of the associated features of childhood Sjögren's. ■

*"It takes an army" continued from page 1 ▼*

From the release of the first-ever Clinical Practice Guidelines (CPG) for the treatment and management of Sjögren's patients to the increase of clinical trials for Sjögren's and the number of awareness events held around the country, our volunteers, donors and corporate partners have helped us make momentous strides in three key areas:

- Increasing public and professional awareness
- Increasing involvement from our friends and partners
- Increasing education and awareness among healthcare professionals

Although our work is far from being done, the SSF has seen our years of hard work and perseverance finally paying off! We are proud of our accomplishments and would like to share some of them with you!

## Increasing public and professional awareness

It is hard to believe that four years have past since the SSF announced the launch of our *5-Year Breakthrough Goal*:

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

After another great year of increasing awareness, the SSF once again worked with a marketing research company to conduct our annual survey of newly diagnosed patients. The SSF is proud to announce that through this survey, it has been determined that it currently takes an average 3.5 years to receive an accurate diagnosis!

That is the third year since announcing our Goal that we have seen a decrease in the time it takes to diagnose Sjögren's and we couldn't be more excited!

When the Goal was first launched, research showed that Sjögren's patients searched for over five years to receive an accurate diagnosis – an amount of time that the SSF Board of Directors and our medical professionals felt was way too long. This prompted them to set the Goal to decrease that time to under 2.5 years by the end of 2017.

The Foundation knows that all patients will benefit from shortening the diagnosed time because as physicians begin seeing more patients in their practices, they will be forced to become more knowledgeable about the different manifestations of Sjögren's and the treatment options available. Thus, newly diagnosed patients and

*continued page 12 ▼*



## SSF in Action! American College of Rheumatology Update



The American College of Rheumatology (ACR) annual conference took place in San Francisco, CA from November 6-11th, 2015. This is the largest rheumatology conference in the country with over 13,000 rheumatologists and researchers from around the world in attendance.

This is an exciting conference for the Sjögren's Syndrome Foundation (SSF)! It gives us a chance to see the many Sjögren's specialists from around the globe in one place. The week is rich with clinical sessions, research discussions and networking meetings.

Every year the SSF has an exhibit at the conference. This year's exhibit was once again in a prime location on the exhibit floor, offering us tremendous exposure to attendees. Those who visited our booth were able to take materials and learn about the Foundation, what we can offer professionals and patients, and get connected with the Foundation to begin receiving up to date resources and information on Sjögren's right to their offices!

There were several clinical sessions on Sjögren's this year. There were two "Meet the Professor" sessions on controversies in Sjögren's led by Fred Vivino, MD, MS. These special programs have limited seating and must be signed up for in advance. Both sessions reached their maximum capacity for participants. Two other great programs offered were

Steven Taylor (SSF CEO), Dr. Nancy Carteron (Chair of the SSF Medical & Scientific Advisory Board), and Dr. Erlin Haacke (SSF 2015 Outstanding Abstract Awardee)

*Immunological Mechanisms in Sjögren's* and an exciting session titled *New ACR-EULAR Sjögren's Classification Criteria and Updates*, which had a packed house with standing room only!

Every year some wonderful research on Sjögren's is presented via ACR's poster and oral abstract sessions. There were over 75 different types of Sjögren's research presented this year in different posters. There were two oral sessions dedicated to covering current research being done both on basic Sjögren's science and new clinical discoveries. The SSF is excited to have had the opportunity to share the research that has been done on Clinical Practice Guidelines for Oral, Ocular and Rheumatologic questions.

An exciting session that is always well attended at the conference is the annual Sjögren's Study Group. At the study group, the SSF presented their Outstanding Abstract Award to Dr. Erlin Haacke for her work entitled *Salivary Gland FcRL4+ B-Cells Are a*

*Potential Source of Progenitor Cells for MALT Lymphoma in Primary Sjögren's*. The study group then continued with a presentation of pulmonary manifestations of Sjögren's present-

*continued page 13 ▼*



*"It takes an army" continued from page 10 ▼*

those diagnosed many years ago will benefit from this increased interest, knowledge and education among healthcare professionals!

To help increase awareness, the SSF Awareness Ambassadors have been on the front lines by helping distribute Sjögren's educational information throughout their local communities. In 2015, 517 volunteers stepped up to be a part of this program and donate their time. Last year's campaigns focused on helping to educate two specific medical fields:

- Rheumatologist
- Primary Care Providers

With the help of our Ambassadors, over 30,000 Sjögren's brochures have been distributed to medical professionals this past year! As our Ambassadors are currently re-committing to be apart of the program in 2016, the SSF would like to thank everyone who participated in our past campaigns. If you would like to serve as an Ambassador in the upcoming year, we encourage you to visit our website at [www.sjogrens.org](http://www.sjogrens.org) to sign up and learn more about the program.

The Foundation also uses our online presence and social media outlets to reach out to the masses by making information easy to access and share. The SSF blog, *Conquering Sjögren's* was launched simultaneously with our Goal as a way for both diagnosed and undiagnosed patients to learn about the various manifestations of the disease. This blog alone has over 3,500 subscribers and over 1,200,000 views! If you are not already a subscriber, you can view our blog by visiting [www.sjogrens.org](http://www.sjogrens.org).

### Increasing involvement from our friends and partners

This is one of the most critical aspects to achieving our Goal because the involvement from our friends and partners helps strengthen our voice!

The SSF strongly values our partnerships with other autoimmune disease organizations, especially those that regularly coincide with Sjögren's. Currently, the SSF is represented on over 10 coalitions (including: Consumer

Healthcare Products Association; National Coalition of Autoimmune Patient Groups, National Health Council, American College of Rheumatology's Access to Accessible Treatment) to advocate and ensure Sjögren's patients

are represented in the healthcare debate. This presence has helped change the way Sjögren's is viewed within the healthcare policy community, on Capitol Hill as well as among our elected officials.

As you have seen in past issues of *The Moisture Seekers*, we continually ask everyone to become involved with

the SSF to help us spread the word by participating in awareness events and other activities. Our *Sjögren's Walkabouts*, *Sip for Sjögren's*, *Team Sjögren's Marathon Races*, *Team Sjögren's Goes Turkey*, and *Bold Blue Day* programs allow patients to connect in a casual and fun



environment that increase both general awareness in their communities and raise funds. By working together with the many volunteers and participants in each community, our events alone raised over \$500,000 to support the

SSF's scientific initiatives, research and patient programs! If you have ever thought about getting involved in one of our events or programs, make 2016 the year you connect with the Foundation!

### Increasing education and awareness among healthcare professionals

A comprehensive understanding of Sjögren's by healthcare professionals is one of the most vital aspects of both the SSF's mission and overall strategy to achieving our Goal. The Foundation continues to work on increasing our visibility at healthcare professional conferences to promote SSF initiatives, programs and distributed mate-



*As patients also know, Sjögren's can often be overlooked or misdiagnosed because symptoms can manifest in various ways and the disease can affect every body system. This is why the SSF works diligently at educating all specialties within the medical community, while also raising awareness in the general public to encourage those suffering from symptoms to be their own health advocate by knowing Sjögren's!*

rials to help practitioners understand both the severity of the disease and how best to treat patients.

As many of you know, the SSF has been developing CPG recommendations for medical practitioners in three categories: rheumatology, oral medicine/dentistry and eye care providers. These guidelines will help standardize patient care by giving physicians a roadmap of how to treat and manage their Sjögren's patients. Currently, over 200 medical professionals are donating their time by serving on an SSF committee to make these guidelines a reality!

In 2015, the SSF released and published the first ever CPG for Sjögren's Ocular Management. These guidelines give physicians a treatment algorithm of how to treat their dry eye Sjögren's patients! And our first set of oral guidelines, focused on Sjögren's dental decay preventative care, will be published in early 2016.

As for rheumatology guidelines, work continues on 16 systemic manifestation guidelines, which will each be published as they are finished and peer reviewed. The first three were submitted in late 2015 for peer review with hopes to be published in mid-2016. The SSF first chose to tackle: *Fatigue and Sjögren's, Inflammatory Musculoskeletal Pain, and Use of Biologics in Treatment of Sjögren's*. And work now continues on the remaining 13 topic areas that include such items as lymphoma, internal organ involvement and neuropathies.

In conjunction with CPG Initiative, the SSF has also been actively working to grow the SSF clinical trials consortium (CTC), which encourages the availability of more therapies for Sjögren's.

Currently there are over 16 compounds/ molecules under review for clinical trials in Sjögren's. The SSF is working alongside each of the companies that have a compound/molecule to help them understand Sjögren's, our patient community and encourage them to develop a treatment for our disease. This could lead to the first systemic treatment for Sjögren's.

To help these companies as well as the U. S. Food and Drug Administration understand what patients are suffering from and what they want a treatment for the SSF will be reaching out to you to ensure your voice is heard!

In the upcoming months, the Foundation will be surveying all SSF patient members about their numerous complications and the burden of their illness on their quality of life in order to share the results with our pharmaceutical partners, as well as the U. S. Food and Drug Admin-

istration. We are doing all of this in an effort to convince them that a therapy for Sjögren's is needed NOW!

## Summary

The dream of making Sjögren's a household name is in our grasp but we still need your help. We need your support by volunteering, donating and continuing to spread the word about Sjögren's. We encourage you to look for opportunities in this and future issues of *The Moisture Seekers* newsletter for ways to connect with the SSF. Patients deserve a better treatment option and a shorter diagnosis time – the time is now to make this happen!

It will take an army, but by talking with one person at a time, one community at a time, one physician at a time and one company at a time – we will reach our goal and transform the future of Sjögren's! ■



## “SSF In Action” continued from page 11 ▼

ed by Thomas Mandl, MD, PhD from Lund University, Lund, Sweden. Tom Gordon, MD, PhD, FRCPA, FRACP from Flinders University School of Medicine, South Australia shared his work of analyzing serum autoantibody repertoires in Sjögren's by proteomics. The Study Group concluded with a lively question and answer session for the presenters and a few other Sjögren's specialists. The Study Group was coordinated and moderated by Hal Scofield, MD from the Oklahoma Medical Research Foundation.

The SSF annual luncheon meeting was also a great success! This annual luncheon is attended by key researchers and clinicians working in the field of Sjögren's and is a wonderful opportunity to bring together those who are passionate about making a difference in Sjögren's. The topic this year was *Expanding Our Clinical View of Sjögren's* and had wonderful presentations from specialists in pediatrics, neurogastroenterology and urogynecology.

The SSF is so grateful for all of this year's presenters and moderators for helping to spread knowledge about Sjögren's throughout the clinical and research communities! ■

# 2016

National Patient Conference

**April 8-9, 2016**

Hilton Seattle Airport &  
Conference Center  
17620 International Boulevard,  
Seattle, Washington

## Save The Date “The Sjögren’s Journey”



This April we invite you to join with fellow Sjögren’s patients, their families, medical experts, the SSF staff and industry/ product exhibitors for our 2016 National Patient Conference, “The Sjögren’s Journey,” at the Hilton Seattle Airport & Conference Center (Seattle, Washington).

Sjögren’s is not the same for every person diagnosed, which is why educating yourself on the most up-to-date information and treatment options is so important. Attending the SSF National Patient Conference is one way you can gain information from many different sources while also meeting fellow patients.

**This year’s Conference will include opportunities to:**

- Hear from national Sjögren’s experts, researchers and SSF staff
- Find new products and receive free samples at our exhibitor hall
- Learn from your fellow patients
- Browse Sjögren’s resources at the SSF Book Table
- Become inspired during the Conference’s Awards Banquet Dinner

We encourage you to take this opportunity and travel “The Sjögren’s Journey” with us. This two-day educational experience will give you the tools to take control of your health and learn how to manage and understand your Sjögren’s symptoms and complications.

Watch for your conference brochure coming in January or visit [www.sjogrens.org](http://www.sjogrens.org) to see updated Conference information.

**Presentation topics will include:**

- Sjögren’s Overview
- Dry Skin and Dermatological Issues
- Oral & Ocular Manifestations of Sjögren’s
- Examining Sjögren’s – Case by Case
- Tips for Your Sjögren’s Journey
- Gynecological Issues with Sjögren’s
- An Inside Look at Sjögren’s and Gluten-Free Diets
- Sjögren’s – Where Are We in Drug Development?

Space is limited. Please register early!

# Registration Form

Registration fees include: Friday evening dinner, Saturday's lunch, hand-out material from speakers and entrance to exhibit area on Friday and Saturday.



## 2016 NATIONAL PATIENT CONFERENCE SEATTLE, WASHINGTON — APRIL 8-9, 2016

### 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 15, 2016)

#### SSF Members & Guests

Non-Members

March 15<sup>th</sup> and before

\$170 per person

\$190 per person

March 16<sup>th</sup> and after

\$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 20<sup>th</sup> 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.
  - I would like a vegetarian meal
  - I would like a gluten-free meal
- A limited number of rooms are available, on a first-come basis, at the Hilton Seattle Airport & Conference Center (17620 International Boulevard, Seattle, WA 98188) at the SSF rate of \$129 per night plus tax if reservations are made by March 15, 2016. Call the toll-free hotel Central Reservations number at (800)-Hiltons or call the Hilton Seattle Airport & Conference Center directly at (206) 244-4800 and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.
- The Hilton Seattle Airport & Conference Center is approximately 1/4 mile from the Seattle-Tacoma International Airport. The hotel offers a 24-hour complimentary shuttle service to and from the airport. Alternate transportation suggestion: Taxi Fare/\$12 (one way).

**QUESTIONS?** Call 800-475-6473 or visit [www.sjogrens.org](http://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*

## 2016 SSF Special Event Calendar

SSF events are organized in an effort to increase Sjögren's awareness in local communities, while raising funds to support research & education. They are also an excellent opportunity to connect Sjögren's patients and their families to others living with the disease.

*If there is already an event in your area and you would like to get involved, or learn about starting one, please visit [www.sjogrens.org](http://www.sjogrens.org) or contact us at (301) 530-4420 x207*

### February

**20** *Phoenix Walkabout and Health Fair*  
 Paradise Valley Mall, Scottsdale, Arizona

### April

**8-9** *National Patient Conference*  
 Hilton Seattle Airport, Seattle, Washington

**9** *Seattle Walkabout (NPC Event)*  
 Hilton Seattle Airport, Seattle, Washington

**TBA** *New York City Sip for Sjögren's*  
 TBA, New York, New York

**TBA** *Triangle Sip for Sjögren's*  
 TBA, North Carolina

### May

**1** *Atlanta Sip for Sjögren's*  
 Nelson Mullins, Atlanta, Georgia

**7** *Philadelphia Walkabout and Health Fair*  
 Philadelphia Zoo, Philadelphia, Pennsylvania

**21** *Northeast Ohio Walkabout*  
 Oak Grove Picnic Area, Brecksville, Ohio

### June

**4** *Denver Walkabout and Health Fair*  
 Hudson Gardens, Littleton, Colorado

**4** *Dallas Walkabout and Health Fair*  
 Parks at Arlington, Arlington, Texas

**11** *Greater Washington Region Walkabout*  
 Two Democracy Plaza, Bethesda, Maryland

