Pregnancy and Sjögren’s: Congenital Heart Block

by Nancy Carteron MD, FACR, Consultant Rheumatologist

Fortunately, congenital heart block (CHB) is rare, but it is the most serious potential complication of pregnancy in Sjögren’s and is largely associated with maternal SSA (Ro) and/or SSB (La) autoantibodies. Most problems can be prevented by knowing your autoantibody status prior to pregnancy, consulting with a high-risk fetal maternal specialist, establishing a team (obstetrician, high-risk OB, rheumatologist), and monitoring during pregnancy. **Knowing your autoantibody profile and levels are important.**

Higher levels of SSA and/or SSB antibodies are associated with increased risk of CHB. In addition to SSA/SSB antibodies, antibodies to RNP (ribonuclear protein) and phospholipids are useful to know. Other factors that may be

Chronic Dry Eye and Sjögren’s

The recent Living with Sjögren’s: Summary of Major Findings patient survey, conducted by Harris Poll on behalf of the Sjögren’s Syndrome Foundation (SSF) showed that 92% of Sjögren’s patients suffer from dry eye. Chronic dry eye has two main causes: decreased secretion of tears by the lacrimal (tear-producing) glands and loss of tears due to excess evaporation. Both can lead to ocular surface discomfort, often described as a feeling of dryness, burning, sandy/gritting sensation, itchiness, visual fatigue, sensitivity to light and blurred vision.

In Sjögren’s, a person’s white blood cells mistakenly invade moisture-producing glands and affects the entire body, including the lacrimal glands, causing inflammation and reducing secretion, which causes dry eye to be one primary symptom of the disease. The challenge is that normal healthy tears contain a complex mixture of proteins...
risk factors include pre-conception inflammatory markers such as CRP (C-reactive protein) and/or ESR (sedimentation rate); degree of active disease; and any prior pregnancy complications.

CHB occurs when there is a delay or block in the electrical transmission within the heart necessary for normal function, and the heart rate slows (bradycardia). The autoantibodies are passively transferred to the baby in utero and can be found within the fetal heart where they can lead to inflammation and damage (scarring/fibrosis). Only 2% of babies of women with SSA/SSB antibodies will have some degree of CHB. The risk does increase 10-fold (18%) if the woman had a previous child with CHB, and 5-fold with neonatal lupus.

Varying degrees of heart block can occur (1st and 2nd degree) with 3rd degree being the most severe (complete heart block). Fetal Pulsed Doppler echocardiograms are usually performed weekly from 18 to 24 weeks gestation, with the American Heart Association suggesting a 16 to 28-week time frame. First degree heart block is most often monitored with no treatment indicated. Second degree heart block often progresses to complete heart block, so treatment is recommended. Fluorinated glucocorticoids, steroids which cross the placenta, such as dexamethasone or betamethasone are taken orally daily. Weekly fetal heart monitoring continues. Steroids are not effective in reversing complete heart block. Based on the monitoring studies, placement of a fetal pacemaker may be necessary. Hydroxychloroquine (400 mg/d) may be started (6-10wk) to optimize dose by 16 weeks in some situations.

Other fetal heart complications can occur but are very rare. These include an enlarged heart (dilated cardiomyopathy), inflammation or scarring within the heart (myocarditis/endocardial fibrosis), and valve dysfunction. A pediatric cardiologist would often join the team to co-manage these conditions.

There is a future consideration for women who have no symptoms and have not been previously diagnosed with an autoimmune disease who have a child with CHB. These women are at increased risk of developing an autoimmune disease like Sjögren’s or lupus in the future (up to 50%), and should seek consultations if unexplained symptoms develop.

In summary, by assessing individual risks and establishing a trusted management team most Sjögren’s pregnancies will be successful!

To learn more about pregnancy in Sjögren’s, view Dr. Cateron’s SSF Patient Education Sheet on page 13.
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• Not intended to prevent xerostomia or oral mucositis.
• Patients should avoid eating or drinking for at least 15 minutes after use.
• Solution should not be swallowed but be spit out.
• Not intended for systemic use to treat any diseases of the throat or upper gastrointestinal tract.
• Not intended for use as an antacid.
• No adverse events anticipated if swallowed accidentally.
• Contains sodium; if you are on a low sodium diet consult with your doctor.
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*In a clinical study patients with varying degrees of xerostomic symptoms (n=30), reported improvement at 28 days.
“Dry Eye” continued from page 1 ▼

and other components that are essential for ocular health comfort (see Figures 1, 2 and 3 below) and this complex mixture is compromised with Sjögren’s.

Congress officially declared July “Dry Eye Awareness Month” in 2005 to help educate the public about chronic dry eye symptoms and treatment options. During the month of July, the SSF partners with other organizations to help educate eye care professionals about the importance of properly treating patients with dry eyes and the possibility of an underlying medical condition like Sjögren’s. In honor of Dry Eye Awareness Month, this issue of The Moisture Seekers is featuring articles that promote dry eye education.

Figure 1

Normal healthy tears contain a complex mixture of proteins and other components that are essential for ocular health and comfort.

Figure 2

Inflammation of tear-secreting glands reduces tear production.

Figure 3

Artificial tears contain water, salts, and polymers but lack the proteins found in natural tears.

continues page 6 ▼

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O
n April 3, 2018, Matt Makara, SSF Director of Research and Scientific Affairs, attended a workshop hosted by the U.S. Food and Drug Administration (FDA) entitled, “Center for Drug Evaluation and Research (CDER) and You: Keys to Effective Engagement.” Throughout the day, a variety of presenters, including FDA staff and representatives from patient advocacy groups, provided information on best practices for working with the FDA as well as the various pathways that are available to pursue, including patient-focused drug development meetings, the Patient Representative Program and listening sessions.

During the workshop, the FDA representatives provided an overview of CDER and demonstrated their new, more efficient, system for non-industry stakeholders to request meetings. Notably, speakers talked about the draft guidance on methods for collecting patient experience data from external stakeholders, which will be the first in a series of related guidance documents.

In addition to the SSF’s engagement with the FDA to represent the patient voice, the Foundation is also working with pharmaceutical companies investigating Sjögren’s therapies to ensure therapeutics are developed that meet the needs of patients. Ten years ago, there were no clinical trials for systemic therapies for Sjögren’s and decisions about Sjögren’s policy issues were made with little input from patients. But today, thanks to you and your support of the SSF, Sjögren’s is recognized nationally and there are 25 systemic therapies from 12 companies that are in clinical trials or in the planning stages.

The SSF is honored to serve as your voice, representing Foundation members and all Sjögren’s patients in our advocacy efforts. We are excited for what the future holds and keeping you updated on our journey of bringing a systemic therapeutic for Sjögren’s to the market! If you are interested in learning more about current clinical trials in Sjögren’s, please visit www.sjogrens.org.
“Dry Eye” continued from page 4 ▼

Sjögren’s Dry Eye Survival Tips

• Try sterile eyelid cleansers or baby shampoo on a warm washcloth to help with blepharitis, a common condition in Sjögren’s that causes chronic inflammation of the eyelids and eyelid margins.

• The mainstay of treatment for blepharitis, a chronic condition that accompanies dry eye and Sjögren’s, is warm compresses, lid massage and lid hygiene. If the blepharitis is acute, you might need a prescription antibiotic ointment.

• If your eyes are bothered by light, wear sunglasses or try lenses with a FL-41 filter.

• Carry a wet washcloth in a zip-top bag to place on your dry eyes when traveling.

• Avoid applying anything to the eyelids that can irritate your dry eye; products placed on the eyelid will get into the tear film.

• Sjögren’s patients with dry eye should carefully clean their eyelids with warm water or one of the commercially available eyelid cleansers.

• Use non-preserved artificial tears frequently and regularly, even when your eyes feel good. The goal is to keep your eyes comfortable, not to wait until they are uncomfortable.

• Keep the upper and lower eyelids free of facial creams at bedtime; they can enter the eye and cause irritation.

• Dry eye patients often develop or aggravate their environmental allergies. An over-the-counter allergy drop (even if preserved) used twice daily may help.

• Try ointments or gels at bedtime by first applying them only to the eyelids and lashes. If that is not helpful, place ~1/4 inch of ointment between the lower lid and eyeball.

• Eye ointments and gels can blur your vision and are usually reserved for overnight use.

• For dry eye, apply a warm, wet compress to the closed eyes using a washcloth. Apply at bedtime and upon awakening for five minutes, or more often if helpful.

• If your vision is blurred with artificial tear, try a less thick (viscous) drop or ointment.

• Try moisture chamber glasses, wrap-around sunglasses, or other glasses, goggles or shields to prevent moisture evaporation and offer protection from air currents that irritate your dry eye.

View more survival tips for Sjögren’s patients on the Foundation’s website www.sjogrens.org.

![Common Symptoms Experienced Almost Weekly or More Frequently](chart.png)

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Chronic dry eye does not typically get better on its own, and often times it will get worse. Acupuncture is a very safe treatment, and apart from occasional bruising, its side effects typically include improved sleep quality, relaxation of tense muscles, and a sense of wellbeing.

Can acupuncture increase moisture with dry eyes?

The beauty of acupuncture is that it does not build a dependency and in fact builds independence by helping to rebuild and restore function to various body systems. A study published in the Chinese Journal of Practical Ophthalmology found that patients receiving acupuncture plus lubricant eye drops had a 76.92% improvement in rate of dry eye symptoms. Patients receiving only lubricant eye drops had a 53.85% improvement. Tear film stability improved significantly with acupuncture. Patients receiving acupuncture plus eye drops had a tear film break-up time of 4.03 seconds compared with 2.11 seconds for the eye drop only group. This means that acupuncture resulted in increased tear production and slower tear evaporation, so tears last longer.

Another study, published in Ophthalmology Times, found that acupuncture “significantly improved patients’ subjective assessment of dry eye symptoms, was associated with significant reduction in use of artificial tears at six months, and its benefits lasted for 9-12 months.”

Having an autoimmune disease, like Sjögren’s, can be stressful and overwhelming at times, often leading to poor sleep quality. All of these work against creating and maintaining healthy levels of serotonin, which is fundamental to healthy tear production.

Receiving regular acupuncture helps maintain healthy serotonin levels, as well as to decrease inflammation, increase circulation, and stimulate the nervous system to focus on a specific region, such as the eyes.

What does this mean for Sjögren’s patients?

It means that although you have Sjögren’s and may always have to work to maintain a reasonable number of tears, a combination of diet, stress management, and acupuncture may be able to minimize and help keep your symptoms at bay.

Dr. Townsend, adjunct professor at the University of Houston College of Optometry, says that “the potential patient benefits of acupuncture suggests that, at the very least, we should consider contacting an acupuncturist and explore working together as a possibility.”

Acupuncture has become so popular in the past few years that everyone is adding it to their list of services. Look for a National Certification Commission for Acupuncture and Oriental Medicine (NCCAOM®) board certified acupuncturist who has a minimum of four years of formal training and countless hours of clinical experience to ensure the best possible experience.

References

3. https://www.nature.com/articles/s41598-017-06022-4
Thank you for supporting the 2018 Spring Walk season. This year was very special as we implemented our new name, “Walk for Sjögren’s” and new theme, “Celebrating Our Strength.”

More than 1,000 patients, family members, friends and health care providers joined us to strengthen the fight against Sjögren’s. You raised funds, donated, volunteered and helped us increase awareness of the Walk for Sjögren’s. Thanks to all of your support, hard work, and dedication we raised more than $150,000.

The funds you raised allow us to continue providing programs and services, advocating for patients and funding research for the 4 million people living with Sjögren’s in the country.

2018 Spring Walk for Sjögren’s Events

- **Phoenix Walk for Sjögren’s** – Saturday, March 10, 2018 – Paradise Valley Mall
- **Denver Walk for Sjögren’s** (National Patient Conference) – Saturday, April 14, 2018 – Hyatt Regency
- **Philadelphia Walk for Sjögren’s** – Saturday, May 5, 2018 – Philadelphia Zoo
- **DC Metro Area Walk for Sjögren’s** – Saturday, May 19, 2018 – Lake Fairfax Park
- **Dallas Area Walk for Sjögren’s** – Saturday, June 9, 2018 – Parks Mall at Arlington

Celebrating the Best of the Best!

Every year, we have volunteers who go above and beyond to raise funds. They write letters, make phone calls, secure sponsors, and use social media to reach their fundraising goals.

**Thank you for being a STAR!**

Thank you to our Volunteer Walk Committees, Local Walk Sponsors, and a special thank you to everyone who achieved our “Sjögren’s Star Status” by raising over $1,000 for a Walk for Sjögren’s! View our Volunteer Walk Committees, Local Walk Sponsors, and Sjögren’s Stars, on www.sjogrens.org.

National Walk Sponsor

And a special thank you to everyone who achieved our “Sjögren’s Star” status by raising over $1,000 for a Walk for Sjögren’s! View our Sjögren’s Stars on www.sjogrens.org.
Join us for the 2019 Walk for Sjögren’s!

Next year, we will continue to Celebrate Our Strength! The Walk for Sjögren’s is an opportunity for our Sjögren’s family to come together to celebrate YOU – Sjögren’s patients, and your Circle of Strength – family, friends, health care providers – the people in your lives who push YOU forward every day.

Our goal for the 2019 Walk for Sjögren’s is to expand our Walk program, increase Walker participation, increase donor support, recruit more volunteers and recruit more sponsors. The Walk program is one of our greatest opportunities to raise funds and raise awareness in the local community that will help us make a difference, WE NEED YOU!

- Help us increase walker participation!
- Help us engage more doctors in the Walk for Sjögren’s!
- Be a Walk for Sjögren’s volunteer!

If you are interested in getting involved or just want to share your ideas, contact Kisha James at (301) 530-4420 ext.218 or kjames@sjogrens.org.

Each fall your local United Way, Combined Federal Campaign, state employee, and private employer payroll deduction campaigns begin. We hope you will remember the Sjögren’s Syndrome Foundation when choosing where to allocate your donation. (CFC #10603)

Remember, the Foundation has received the:

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Each fall your local United Way, Combined Federal Campaign, state employee, and private employer payroll deduction campaigns begin. We hope you will remember the Sjögren’s Syndrome Foundation when choosing where to allocate your donation. (CFC #10603)

Tell your co-workers, friends, and family members how important it is to choose and write in the Sjögren’s Syndrome Foundation on their campaign form, too.

If your employers will not allow you to write in the Sjögren’s Syndrome Foundation, remind them that we are a national non-profit 501(C3) organization and qualify for most payroll deduction campaigns. If they need more information, please contact the Foundation at 800-475-6473.

Just think – every dollar counts.

Last year alone – thanks to those who chose to give through their employer’s payroll campaign – the Sjögren’s Syndrome Foundation was able to increase its Research and Awareness commitments.
Get what you need and support the Sjögren’s Syndrome Foundation

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The Sjögren’s Syndrome Foundation has partnered with online retailers who will donate a portion of your purchase to the SSF, so shopping online is now an easy way to contribute to Sjögren’s!

Just visit www.sjogrens.org/shopforsjogrens and click through the links provided so that your purchases will benefit the SSF. Once you select the “Sjögren’s Syndrome Foundation” as your charity of choice, whenever you return to these retailers and log in, any shopping you do will benefit the SSF. It’s that simple!

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Amazon is one of the most popular online stores in the world, offering a wide variety of products.

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Get what you need and support the Sjögren’s Syndrome Foundation
Ocular Management in Sjögren’s

The SSF published the Clinical Practice Guidelines (CPG) for Ocular Management in Sjögren’s in 2015. These guidelines are helping to ensure the quality and consistency of care for the assessment and management of Sjögren’s patients who suffer from dry eye. We encourage you to share these guidelines with your eye care provider and talk about the treatment options.

The development of the first-ever U.S. Clinical Practice Guidelines for Sjögren’s is an ongoing initiative of the SSF that began in 2010. To learn more about the development of these guidelines and view the SSF’s Guidelines for Ocular Management in Sjögren’s, please visit https://www.sjogrens.org/home/research-programs/clinical-practice-guidelines.

Do we have your e-mail address?

If you want to receive all the latest updates from the Sjögren’s Syndrome Foundation, then you should make sure we have your most up-to-date e-mail address! The SSF is starting to share more information via e-mail, from news about the SSF and Sjögren’s, to information about the latest treatments and medicines, to local Support Group updates and more. So contact us at ssf@sjogrens.org to be certain we have your latest e-mail address! The SSF is starting to share more information via e-mail, from news about the SSF and Sjögren’s, to information about the latest treatments and medicines, to local Support Group updates and more. So contact us at ssf@sjogrens.org to be certain we have your latest e-mail address.

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Factors contributing to ability to conceive:
- Age
- Primary ovarian failure
- Endometriosis
- Environmental factors (i.e. pesticides)

Potential pregnancy complications:
- Congenital heart block (SSA/SSB autoantibodies; possibly RNP antibodies)
- Neonatal lupus (rash) (SSA/SSB autoantibodies)
- Fetal loss
- Intrauterine growth retardation
- Premature delivery
- Recurrent pregnancy loss
- Preeclampsia (phospholipid autoantibodies)

Know your autoantibody (blood tests) status:
- SSA (Ro) and SSB (La) – higher levels may carry more risk
- Phospholipid antibody (APL) – Lupus anticoagulant; IgG and IgM cardiolipin antibody; IgG and IgM anti-beta2 glycoprotein I antibody

Congenital heart block (CHB) – most serious potential complication:
- First pregnancy – 2% risk
- If previous child had CHB, risk increases 10-fold for subsequent pregnancy
- Weekly Doppler fetal echocardiogram surveillance between the 18th and 20th weeks
- Cardiomyopathy can occur
- Management strategies, including fetal pacemaker available

Neonatal lupus (rash):
- Autoantibodies cross the placenta, decline over several weeks, rash resolves
- If previous child had Neonatal lupus, risk increases 5-fold for neonatal rash for subsequent pregnancy
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‡In people with dry mouth who use 2 discs while sleeping and 4 more during the day.
Each July 23rd, the SSF joins with Sjögren’s organizations around the world to celebrate World Sjögren’s Day, which commemorates the birthday of Dr. Henrik Sjögren, a Swedish ophthalmologist who first identified the disease in 1933.

World Sjögren’s Day is an opportunity to recognize advancements made in Sjögren’s this past year and the incredible progress the SSF has made on behalf of Sjögren’s patients. More importantly, it is a way to help raise awareness of this complex disease and funds for future research.

Thank you to everyone who helped celebrate World Sjögren’s Day by sharing your story or donating to the Foundation’s research efforts. Together, we are transforming the future for all Sjögren’s patients!