

Q&A ASK THE EXPERTS

Q *Is it recommended that I get the flu shot?*

A As a patient with Sjögren's you are wondering about whether or not you should receive a flu vaccine this year. I do believe it is important to gain some knowledge about the flu.

First let's learn about last year's flu season. The 2018-2019 influenza season was moderately severe, with activity beginning to increase in November, peaking in mid-February, and returning to below baseline in mid-April.

continued page 2 ▼

Q *The use of CBD oil has been in the news a lot and I've heard it mentioned to help treat Sjögren's. What is CBD oil, how can it be used to treat Sjögren's patients and has this treatment been approved to be safe?*

A With our current opioid crisis along with the increasing approval of the use of medical cannabis in the United States, this is a timely and appropriate question. Cannabis (also known as marijuana) is the most commonly used illegal drug worldwide (at least illegal in most areas). The compound called delta 9-tetrahydrocannabinol (THC) is responsible for its effects that make people feel "high." Another compound in cannabis is cannabidiol, known as CBD for short. CBD does not have the "high" exerting effects of THC but is thought



to have medicinal effects partly due to its attachment to cannabinoid receptors. These receptors are located on the surfaces of cells throughout the body to include the brain, nerves, and cells of the immune system. Therefore, it is not surprising that CBD may potentially have beneficial health properties.

continued page 4 ▼



Board of Directors

Chairman of the Board

Janet E. Church

Chairman-Elect

Kathy L. Sivills, PhD

Treasurer

Monica McGill, EdD

Secretary

Tricia Gooding

Esen K. Akpek, MD

Susan Barajas

Patricia Hurley, MSc

Chadwick Johr, MD

Theresa Lawrence Ford, MD

Scott Lieberman, MD

Cynthia Lopynski

Jonathan Morse, MSc

Jason Nichols, OD

Timothy Niewold, MD, FACP

David Schrader

Thomas D. Sutton

Donald E. Thomas, MD

Michelle Wallace

Ava Wu, DDS

Medical & Scientific Advisory Board

Chairman

Theresa Lawrence Ford, MD

Esen Akpek, MD

Richard Brasington, MD, FACP

Michael T. Brennan, DDS, MHS

Steven E. Carsons, MD

Nancy L. Carteron, MD, FACP

Troy Daniels, DDS, MS

Denise Faustman, MD, PhD

H. Kenneth Fisher, MD, FACP, FCCP

Gary Foulks, MD, FACS

S. Lance Forstot, MD

Phillip C. Fox, DDS

Robert I. Fox, MD, PhD, FACP

Tara Mardigan, MS, MPH, RD

Austin Mircheff, PhD

John Daniel Nelson, MD, FACS

Kelly Nichols, OD

Athena Papas, DMD, PhD

Ann Parke, MD

Andres Pinto, DMD

Nelson Rhodus, DMD, MPH

Vidya Sankar, DMD, MHS

Daniel Small, MD, FACP

Neil Stahl, MD

Frederick B. Vivino, MD, FACP

Jeffrey Wilson, MD, FACP

Chief Executive Officer

Steven Taylor

Senior Director of Marketing/Editor

Elizabeth Trocchio

e-mail: tms@sjogrens.org

www.sjogrens.org

“Q&A: Flu” *continued from page 1* ▼

The 21-week season was the longest in 10 years. CDC estimates that from October 1, 2018 through May 4, 2019, there have been 531,000–647,000 flu-related hospitalizations and 36,400–61,200 flu deaths.

People with flu can spread it to others up to about 6 feet away. Most experts think that flu viruses spread mainly by droplets made when people with flu cough, sneeze or talk and less commonly from surfaces. People with flu are most contagious in the first 3 to 4 days after the illness began. Most healthy adults may be able to infect others beginning one day before symptoms develop and up to 5 to 7 days after becoming sick. Children and some people with weakened immune system may pass the virus for longer than 7 days.

Antiviral drugs can lessen symptoms and shorten the time you are sick by 1 or 2 days. They also can prevent serious flu complications, like pneumonia. For people at high risk of serious flu complications, treatment with antiviral drugs can mean the difference between milder or more serious illness possibly resulting in a hospital stay. CDC recommends prompt treatment for people who have influenza infection or suspected influenza infection and who are at high risk of serious flu complication.

An annual seasonal flu vaccine is the best way to help protect against flu. Vaccination have been shown to have many benefits including reducing the risk of flu illness, hospitalizations and even risk of flu reiterated complications. Flu vaccine cause antibodies to develop in the body about 2 weeks after vaccination. These antibodies provide protection against infection with the viruses that are in the vaccine.

The seasonal flu vaccine protects against the influenza viruses that research indicates will be the most common during the upcoming season. Traditional flu vaccine (called “trivalent” vaccines) are married to protect against three flu viruses and influenza A (H1N1) virus, and influenza A (H3N2) virus, and an influenza B virus. There are also flu vaccines made to protect against four flu viruses (called “quadrivalent” vaccines). These vaccines protect against the same viruses as the trivalent vaccine and an additional B virus. Patient’s over age 65 need high-dose vaccine.

Annual vaccination against seasonal influenza is recommended for all U.S. persons aged ≥ 6 months. Effectiveness of seasonal influenza vaccine varies by season.

A paper by Wahren-Herlenius and colleagues, published in 2017 addressed the effect of H1N1 flu vaccine in patients with Sjögren’s syndrome. Untreated Sjögren’s patients had an exaggerated response with

continued page 4 ▼

The Moisture Seekers® Newsletter is published by the Sjögren’s Syndrome Foundation Inc.,
10701 Parkridge Boulevard, Suite 170, Reston, VA 20191.

Copyright ©2019 Sjögren’s Syndrome Foundation Inc. ISSN 0899-637.

DISCLAIMER: The Sjögren’s Syndrome Foundation Inc. in no way endorses any of the medications, treatments, or products mentioned in advertisements or articles. This newsletter is for informational purposes only. Readers are advised to discuss any research news, drugs, treatments or products mentioned herein with their healthcare providers.



Are you looking for a meaningful volunteer experience?

Interested in making a difference in the lives of other Sjögren's patients?

Join us as a Patient Support Volunteer!

Patient Support Volunteers are seasoned Sjögren's patients who are willing to receive calls from newly diagnosed Sjögren's patients. You will provide them with support and Sjögren's information, especially about day-to-day living, coping strategies and available resources. The SSF is looking for qualified volunteers throughout the country to be part of our growing network of support!

If you are someone who:

- Has been diagnosed with Sjögren's for 1 year or more
- Has been a member of the SSF for at least 6 months
- Is knowledgeable about Sjögren's and the resources available to newly diagnosed patients
- Is known for being a great listener and having a positive outlook



This could be the perfect volunteer opportunity for you!

If you are interested in becoming part of our team of volunteers and would like more information visit www.sjogrens.org and sign up under the "Get Connected" tab and select "Volunteer as Patient Support" or contact Kathy Ivory at kivory@sjogrens.org or call (301) 530-4420, ext. 203.

“Q&A: Flu” *continued from page 2* ▼

higher IgG levels to H1N1 flu vaccine, hydroxychloroquine-treated patients did not show any exaggerated response.

To summarize, I strongly recommend inactivated injectable flu vaccines for Sjögren’s patients but caution is warranted when considering vaccination in

non-treated Sjögren’s patients who have really active disease with multi-organ involvement. The patients on immunosuppressive medications (like prednisone, methotrexate, azathioprine, mycophenolate mofetil, rituximab) should not receive live attenuated influenza vaccine (the nasal spray flu vaccine).”

Mehrnaz Maleki Fischbach, MD

“Q&A: CBD Oil” *continued from page 1* ▼

CBD oil is an oil substance that contains CBD. Its medical use has been purported to possibly help with pain, epilepsy, insomnia, anxiety, glaucoma, appetite loss, and muscle spasms. A cannabis extract with THC and CBD called Sativex is approved for use in at least 27 countries, excluding the US, to treat the pain and muscle spasm of multiple sclerosis, and the CBD extract called Epidiolex has been FDA approved to treat childhood epilepsy. Upon a careful search of the medical literature, I was unable to find any good research addressing its use in Sjögren’s syndrome. Its effects on the immune system in autoimmune diseases, such as Sjögren’s, is currently unknown. There are two types of cannabinoid receptors on immune cells; the activation of one of them can increase inflammation, while activation of the other can decrease it. Clearly, we need good research.

Unfortunately, research into the effects and use of CBD has been greatly hindered because the U.S. government classifies CBD under Schedule I: “high potential for abuse” under the United States Controlled Substances Act making it illegal to possess or use under federal law (though it has been legalized by most states). Unfortunately, this Schedule I classification has kept researchers from truly testing it as you would any medical treatment.

Thus far, side effects have been noted in cannabinoid products to include rash, diarrhea, vomiting, fatigue, drowsiness, low blood pressure, high heart rate, light headedness, worsening of Parkinson’s disease, and dry mouth (important when we are talking

about Sjögren’s). They also appear to probably have potential harmful interactions with other medications and supplements to include melatonin, valerian root, SAME, antibiotics, antidepressants, antihistamines, blood pressure medicines, warfarin, anti-acids, statins used for cholesterol, seizure medicines, and Viagra.

I have had patients with chronic pain use CBD oil and purportedly report good results, especially for nerve pain (which is common in Sjögren’s). However, I am unable to formally recommend it to my patients for several reasons. One big reason is that recently there have been reports of high levels of pesticides and heavy metals (such as arsenic and lead) in many CBD products along with inaccurate amounts of the stated amounts of CBD. This represents one of the biggest problems. Since the federal government makes CBD use illegal, there is no quality regulations imposed on their production and distribution. One of the most important things is that I cannot recommend any treatment unless it has been proven safe plus effective. We just do not have the research to prove either one.

Bottom Line: I do believe that it may have potential health benefits. However, until we have more studies to prove effectiveness that outweighs side effects, studies to know its potential interactions with other medications, and that we have regulatory controls to ensure high quality products (devoid of harmful contaminants), I cannot recommend it.

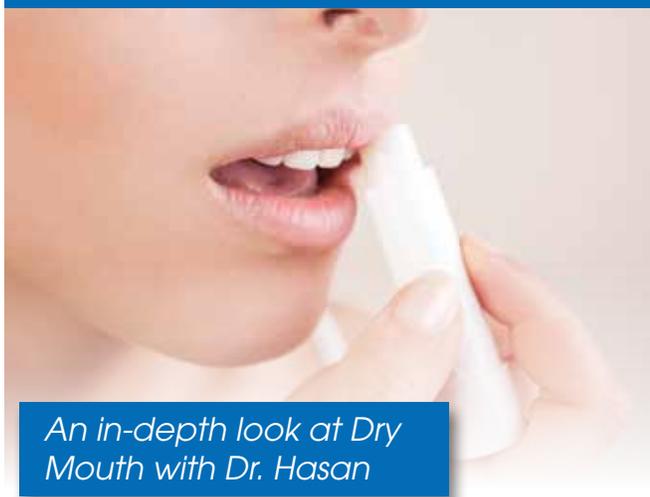
Donald E. Thomas, Jr., MD, FACP, FACR, RhMSUS, CCD

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! Learn news about the SSF and Sjögren’s, 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 in our database.

Just like all information you give the Foundation, your e-mail address will remain private and will never be given or sold to an outside organization.

Q&A ASK THE EXPERTS Continued



An in-depth look at Dry Mouth with Dr. Hasan

Q *What are recommendations for extremely dry lips from Sjögren's? It's not just the pain but they're starting to change color. Is this from Sjögren's?*

A One of the manifestations of Sjögren's is dry lips. When the lips are very dry this may start causing pain, burning or even changing color. Other signs of dryness on the lips are fissuring, exfoliating and bleeding. Keeping the lips properly lubricated and staying hydrated are very important in management of dry lips. There are a few things I would like to recommend you try. Make sure that you drink water very frequently and keep yourself well hydrated. Try Aquaphor Lip Repair, it can safely be used several times a day. It also comes with SPF 30 which may be a better option for you. Other very good and effective products are Dr. Lipp Original Nipple Balm for Lips, Jack Black Intense Therapy Lip Balm SPF 25 & Kiehl's Lip Balm #1. If you do not see any improvement after a couple of weeks, I would suggest seeing either an oral medicine specialist, dermatologist or oral pathologist.

Iqbal Hasan, DDS

Q *What can I do about teeth sensitivity with Sjögren's?*

A Teeth sensitivity could be caused by several reasons and its management largely depends on the cause of sensitivity. Some of the common reasons in patients with Sjögren's are exposed roots, chipped or cracked teeth or worn teeth. Treatment choice will depend on cause of sensitivity as well as severity. Most times desensitizing tooth pastes like Sensodyne and Crest Sensitivity toothpaste may be enough. Other options could be high fluoride toothpaste like Prevident 5000 or applying topical fluoride using a fluoride tray which your dentist can make for you. If gingival recession is the cause, then exposed root surfaces may be protected using bonding agents or gum grafting can be done. In extreme cases where sensitivity becomes unbearable then root canal treatment could be the only option. My suggestion would be to get help from your dentist since they need to evaluate the cause of sensitivity. I would also suggest keeping your mouth well lubricated.

Iqbal Hasan, DDS

Q *My mouth is extremely dry. Before I go to bed at night, I brush my teeth and use mouthwash, but I wake up during the night and have to peel my tongue from the roof of my mouth. Is there anything I can do for night time moisture that won't cause cavities?*

A I would start by suggesting that you make sure your mouthwash does not contain alcohol. If you like using mouthwash then switch to an alcohol free one like TheraBreath, Biotene or ACT Mouth-

continued page 6 ▼

“Q&A” *continued from page 5* ▼

wash for dry mouth. Avoid carbonated beverages and drinks with caffeine in it especially at bedtime. Using oral moisturizing gel maybe helpful too. Then I would like to suggest using a cool mist humidifier and keep it next to your bed. Make sure you keep yourself well hydrated during the day and drink enough water. This is something chronic and does not improve very quickly, it is a process which takes time. You may need to give a few days to a couple of weeks to see any change.

Iqbal Hasan, DDS



Q *What are side effects of taking low dose prednisone every day? It's the only thing that helps with my pain, but I hear that it's not a long-term solution.*

A Prednisone belongs to the class of medications known as corticosteroids (or anti-inflammatory agents). These medications provide relief of inflammation and are used to treat a variety of medical conditions including pain, asthma, Sjögren's and rheumatoid arthritis. As with all medications, corticosteroids have some adverse side effects related to the dose and the duration in which the medication is taken. Side effects associated with low dose (7.5 mg/day or less) daily prednisone are less severe than those seen with higher doses (greater than 30mg/day) and can usually be managed with precautions. Common side effects of daily low dose prednisone include elevated blood pressure, swelling, changes in blood sugar, increased appetite, weight gain, insomnia, osteoporosis (thinning of bones), irregular menstrual periods, and mood changes. Serious side effects associated with higher doses and long-term use (greater than 1 month) are impaired wound healing, decreased growth (in children), decreased muscle production, fat deposits, stomach ulcers or bleeding, vision problems, higher risk for infection, and in rare cases life-threatening allergic reactions.

Although the list of side effects may make you wonder whether you should take this medication or not, please be reassured that many people take daily low dose prednisone with minor or no side effects. The following self-care tips may help minimize some of the side effects associated with prednisone. For those ex-

continued page 8 ▼

Donate Your Old Vehicle

Call us today for more information.
800-475-6473

Sjögren's Syndrome Foundation

OraCoat XyliMelts® and XyliGel®
for dry mouth

Unlike other oral moisturizers, XyliMelts and XyliGel are non-acidic and will not harm teeth.

OraCoat XyliMelts

- **Rated most effective by dentists***
- Oral adhering discs for use while sleeping and daytime
- Coats, moisturizes and lubricates†
- Stimulates saliva†
- Reduces risk of tooth decay
- Freshens breath
- Reduces plaque by 50%†
- **Mild-Mint and Mint-Free** available

XyliMelts are available at:
RITE AID, CVS pharmacy

Clinicians Report®, March 2016 Dry Mouth Survey Results
In a survey of 1168 dentists about effectiveness of dry mouth remedies, dentists who had experience with OraCoat XyliMelts for dry mouth rated it as more effective than any other non-prescription remedy for dry mouth.*

OraCoat XyliGel
For patients with very low levels of saliva or who prefer a gel
• pH 7.4 neutralizes acids

Call now for a free sample:
855-275-4766
(limit one per household)

XyliGel is available at:
oracoat.com, RITE AID Starting March 25, 2019

*Survey of 1168 dentists, March 2016 Clinicians Report®, an independent, non-profit, dental education and product testing foundation. Citation available at oracoat.com.
†These statements have not been evaluated by the Food and Drug Administration. This product is not intended to diagnose, treat, cure or prevent any disease.
‡In people with dry mouth who use 2 discs while sleeping and 4 more during the day.

SSF in Action!

Future Promise and Critical Research Needs in Special Care Communities



A Summary of an IADR Symposium

On Thursday, June 20th, during the International Association for Dental Research's 2019 General Session held in Vancouver, BC, Kathy Hammitt, SSF Vice President of Medical & Scientific Affairs and Co-Chair of the Friends NIDCR Patient Advisory Committee, participated in an FNIDCR PAC

hosted symposium highlighting special care communities, the latest translational research for these patients and areas of the highest critical need for future research. Joined by an esteemed group of colleagues, the session featured Dr. Athena Papas who discussed improving the quality of oral health for the future, Dr. Tim Wright, who discussed the promise of basic science and translational medicine related to craniofacial diseases and Dr. A. Razzaque Ahmed, who discussed pemphigus and pemphigoid and the effect on the oral cavity. The session was moderated by Dr. Martha Somerman, Director of the National Institutes of Dental and Craniofacial of Research (NIDCR).

Dr. Somerman began the symposium by providing an overview of NIDCR, some of the resources available through the institute and examples of research taking place under their purview related to special care communities. A few examples of

NIDCR-supported research that were mentioned include an online training program in special needs dentistry for dentists in general practice; an instrument to assess dentally-related cognitive function in cognitively-impaired individuals; and the Oral Health Promotion Strategy, which is directed to

caregivers and tailored to the needs of people with intellectual and developmental disabilities. Dr. Somerman also spoke about NIDCR 2030, a strategic plan with focus areas including the synergy between oral and overall health, precision health, autotherapies, biodevices and workforce diversity.

Next, the SSF's Kathy Hammitt spoke on the importance of ensuring the patient voice is included in

research considerations and clinical trials. During this time, Hammitt provided examples of patient feedback on the oral manifestations of their disease and their hope for more and improved options for treatment and care. In addition to providing examples of how patients can be engaged, which included options such as patient surveys, focus groups, interviews and ongoing patient engagement efforts, Hammitt spoke to the critically important concept of patients adopting a new device or therapy, and how a patient's perception



From left to right: A. Razzaque Ahmed, MD, DSc; Athena Papas, DMD, PhD; Tim Wright, DDS, MS; Kathy Hammitt, MA; Martha Somerman, DDS, PhD, Director, NIDCR, NIH.

“Q&A” *continued from page 6* ▼

periencing swelling and/or elevated blood pressure, a healthy low sodium diet, regular exercise, and stress management can help to keep your blood pressure under control while taking daily low dose prednisone. If you have diabetes, it is important to monitor your blood sugar and report any severe fluctuations in blood sugar to your provider. It is recommended that prednisone be taken with food or milk to minimize stomach upset and reduce the chance of stomach ulceration. Schedule yearly eye exams and report any new changes in vision to your eye doctor. Long term corticosteroid therapy may cause thinning of bones (osteoporosis) which increases the risk of bone fracture. Talk to your doctor or pharmacist about vitamin D and calcium supplementation to help protect your bones. Since long term prednisone use can increase your risk for infection, ask your doctor or pharmacist to review your vaccination history and be sure to stay up to date on all of your recommended vaccines. Alert your family members and friends about the possibility of mood changes associated with this medication, so they can help detect any unusual changes in your behavior. Report any changes in mood or behavior to your doctor.

Although experiencing side effects is unpleasant, it is crucial to avoid sudden discontinuation of this medication. Never stop or decrease your dose unless instructed by your doctor. Your doctor can instruct you on how to slowly decrease your dose if you need to stop taking this medication for any reason.

*Ajay John, Pharmacy Intern
Kayli Smith, Pharm.D*

Q *What are some side-effects of pilocarpine? I'm worried about what will happen if I miss a dose.*

A Pilocarpine, in its oral form, is used to treat dry mouth caused by Sjögren's. It belongs to a class of medications known as cholinergic agonists which stimulate the salivary glands to produce saliva and relieve dryness. This medication may take several weeks to alleviate symptoms of dry mouth. This medicine may cause dehydration, blurred vision, or trouble seeing at night. Drink plenty of fluids so you don't become dehydrated. Use caution when driving at night or doing other tasks that require clear eyesight

until you know how the medication will affect your vision. Common side effects include flushing, dizziness, headache, nausea, increased urination, muscle weakness, runny nose, and sweating. If any of these side effects become severe or intolerable, talk to your doctor. Seek immediate medical attention if you experience severe side effects such as signs of an allergic reaction (severe itching or hives, swelling in your face or hands, chest tightness, trouble breathing), swelling of your legs, fast or slow heartbeat, vision changes, excessive sweating, severe dizziness, severe headache, confusion or shaking.

In the case of a missed dose, it is typically safe to take the dose as soon as you remember. However, if you are within 4 hours of your next dose, skip your missed dose and take a dose at your next scheduled time. Do not take extra medication to make up for a missed dose.

*Ajay John, Pharmacy Intern
Kayli Smith, Pharm.D*

Q *My rheumatologist suggested I begin taking Plaquenil. Can you help me understand the side effects and if taking the drug is worth it?*

A Plaquenil (hydroxychloroquine) is an oral medication that is widely used to treat rheumatoid arthritis, and other autoimmune diseases such as lupus and Sjögren's. It can help decrease the pain, fatigue, and swelling associated with arthritis and Sjögren's. Plaquenil is a medication with potential to modify disease progression in a number of patients and decrease the overall "disease activity." Symptoms tend to improve in one to two months, but it may take up to six months to achieve the full benefit of Plaquenil therapy.

Plaquenil is typically well-tolerated, but it can pose serious risks. Less serious side effects include nausea, vomiting, diarrhea, headache, tiredness, and rare color changes of the skin and hair. Some serious side effects include changes in vision with potential for irreversible eye damage, color vision abnormalities, heart irregularities, muscle and nerve weakness, changes in mood or behavior, low blood sugar, dizziness, weight loss, and serious skin reactions. Visual changes are rare and tend to occur in individuals who are taking high doses (300

continued page 10 ▼



Research News

SSF Joins Biomarker Initiative That Could Ultimately Change our Ability to Diagnose, Monitor and Treat Sjögren's

Identification of biomarkers specific to Sjögren's will make a critical difference in diagnosing, monitoring and treating Sjögren's patients. Biomarkers are elements that can be measured in an individual, such as a blood protein. When these biomarkers are unique to a specific disease, they can aid in diagnosis, and when these biomarkers change over time or with a therapy, they can help clinicians monitor disease activity or even tell us how well a therapy is working.

In July 2019, the Sjögren's Syndrome Foundation joined the Foundation for the National Institutes of Health (FNIH) Biomarkers Consortium – a move that will expedite and enhance our community's ability to address some of the most immediate needs in Sjögren's. Established by Congress in 1990, the FNIH is a nonprofit 501(c)(3) charitable organization that creates and manages alliances with public and private institutions to support the mission of the NIH and to accelerate biomedical research and strategies to combat diseases. The FNIH is recognized as a distinguished and accomplished entity that successfully brings multiple stakeholders together and solicits the resources necessary to move major health initiatives forward.

The FNIH Biomarkers Consortium

Within the FNIH is the Biomarkers Consortium. This public-private biomedical research

partnership, established in 2006 as a collaboration among the FNIH, NIH, U.S. Food and Drug Administration (FDA), and PhRMA was formed to discover, develop and seek regulatory approval for biomarkers to support drug development, preventive medicine and medical diagnostics. Comprised of staff from the FNIH, FDA, NIH, Centers for Medicare and Medicaid Services, PhRMA, BIO, pharmaceutical companies and non-profit organizations, the Biomarkers Consortium is helping create a new era of precision medicine, with more highly-predictive markers that have an impact during a patient's illness or lifespan. Through these collaborations, the combined abilities of the involved stakeholders in the public and private sectors can accelerate the development of biomarker-based technologies, medicines and therapies for the prevention, early detection, diagnosis and treatment of disease.

The FNIH Biomarkers Consortium and Sjögren's Working Group

The FNIH Biomarkers Consortium Inflammation and Immunity Steering Committee (IISC) identified Sjögren's as a priority to address in its 2018 strategic plan. Fast-forward to summer 2019, and a dedicated Sjögren's Working Group has been established and is working to prioritize challenges

“Q&A” *continued from page 8* ▼

mg/day or more) for many years, individuals 60 years or older, or those with severe kidney disease. Patients should have an eye exam before starting Plaquenil and every 3 months while on therapy, or as suggested by your doctor. Call your doctor right away if you experience signs of infection (such as fever, chills, or sore throat), have unexplained bruising or bleeding, if you feel constantly tired or weak, if you experience any allergic reactions (such as itching, hives, swelling of the face or hands, chest tightness, trouble breathing), blurred vision, hearing problems, dark urine or pale stools, yellow skin or eyes, fast or uneven heartbeat, or unusual changes in mood or behavior.

Overall, Plaquenil is a well-tolerated and effective medication that helps to alleviate pain and symptoms of arthritis and Sjögren’s. Although the side

effects associated with Plaquenil can’t be avoided entirely, proper monitoring such as routine blood work, laboratory testing, and eye exams can help prevent serious adverse outcomes. As always, call your doctor right away if you experience any adverse effects and, in most cases, prompt discontinuation of therapy can prevent any severe damage.

As with any new medication, it is important to weigh the risks versus benefits of each medication before considering starting therapy. Talk with your doctor about your disease severity, disease progression, symptoms, past medical history, and any predisposing risk factors you may have. These factors should all weigh into your individualized risk assessment to determine if Plaquenil therapy is right for you.

*Ajay John, Pharmacy Intern
Kayli Smith, Pharm.D*

“Research News” *continued from page 9* ▼

and develop a project plan for a partnership addressing the major needs of the Sjögren’s drug development community. Key priorities under consideration for this working group include evaluation of new potential clinical tools to support the clinical development of novel therapies for Sjögren’s. The following challenges have been identified by the working group as key items to address:

- Defining eligible patient subpopulations
- Understanding disease progression
- Biomarker development and characterization
- Identifying and harmonizing appropriate endpoints

Looking Ahead

The SSF and the FNIH Biomarkers Consortium began to explore partnership opportunities during the American College of Rheumatology’s 2018 Annual Meeting in Chicago, IL. The SSF subsequently was pleased to join the FNIH Biomarkers Consortium, and Steven Taylor, SSF

CEO, and Kathy Hammitt, SSF Vice President of Medical & Scientific Affairs, now participate in the Sjögren’s Working Group. Additional Working Group participants include Dr. Theresa Lawrence Ford, SSF Medical and Advisory Board Chair and Chair of the SSF Clinical Trials Consortium and Dr. Daniel Wallace of UCLA and Cedars Sinai as well as two representatives from the NIH and twelve pharmaceutical companies. Hammitt also sits on the FNIH Biomarkers Consortium Inflammation and Immunity Steering Committee that oversees working groups for inflammatory and immunological diseases.

With numerous initiatives on Sjögren’s just now coming into full swing internationally, the FNIH Biomarkers Consortium Sjögren’s Working Group aims to find a unique niche that will enhance and harmonize with these other efforts for a more robust outcome for all stakeholders. The SSF, along with all parties involved, look forward to advancing the field and expediting discoveries that will benefit all patients suffering with this disease. ■

SSF EVENT CALENDAR

To learn more about SSF events, please visit www.sjogrens.org or contact Jessica Levy at (301) 530-4420 ext. 218 or email jlevy@sjogrens.org.



OCTOBER

New Hampshire Area Walk for Sjögren's: In Memory of Karen T. Caron

Sunday, October 6, 2019

Dorrs Pond at Livingston Park, Manchester, NH

Los Angeles Area Walk for Sjögren's

Saturday, October 19, 2019

La Mirada Community Regional Park

NOVEMBER

One Day Sjögren's Patient Conference

Saturday, November 2, 2019

Hilton Garden Inn Cleveland-Downtown

Austin Area Walk for Sjögren's

Saturday, November 9, 2019

Round Rock Premium Outlets

DO YOU HAVE PRIMARY SJÖGREN'S SYNDROME & DRY EYES?

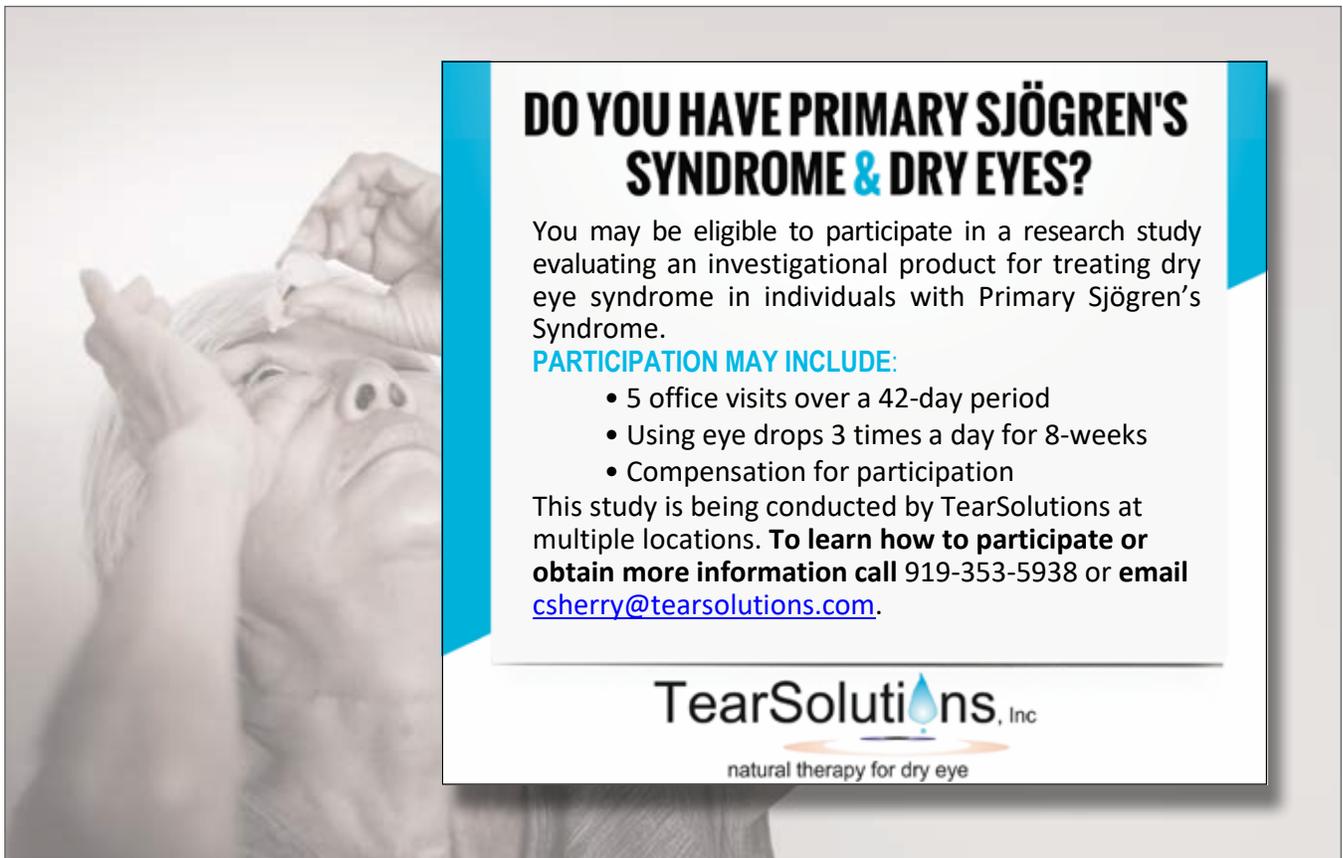
You may be eligible to participate in a research study evaluating an investigational product for treating dry eye syndrome in individuals with Primary Sjögren's Syndrome.

PARTICIPATION MAY INCLUDE:

- 5 office visits over a 42-day period
- Using eye drops 3 times a day for 8-weeks
- Compensation for participation

This study is being conducted by TearSolutions at multiple locations. **To learn how to participate or obtain more information call 919-353-5938 or email csherry@tearsolutions.com.**

TearSolutions, Inc
natural therapy for dry eye



“SSF in Action” *continued from page 7* ▼

that if they don't think it will make them better or the difficulties related to use outweigh the perceived benefits, will ultimately influence them to not use the product.

Dr. Tim Wright followed with a presentation touching on a number of different conditions, including ectodermal dysplasias and hypophosphatasia, with examples of some of the basic and translational research taking place in the fields, including enzyme replacement and gene therapies. Near the end of Dr. Wright's presentation,

he noted that a dental team serves as front line diagnosticians, and that the ability to come to a correct diagnosis is critical for accurate counseling and consideration of appropriate treatments. The final presentation on the panel was given by Dr. A. Razzaque Ahmed who spoke about pemphigus and pemphigoid, noting these conditions are one of the best examples we have that demonstrate the bridge between oral and general medicine. Dr. Ahmed provided numerous examples of these conditions as well as best practices for management and treatment. ■



2020 Is A Year of Change at the Sjögren's Syndrome Foundation

The Future Looks Brighter than ever.

We are excited about the changes that are coming, especially to The Moisture Seekers publication which will see an entire new look, new name and additional content spread among 6 expanded and longer issues.

Watch for our November/December issue for more announcements and a preview of the SSF's new patient newsletter!



You Stood Up!

Celebrating our Strength

On Saturday, May 18th, 2019, the Walk for Sjögren's DC event was held outside of the Sjögren's Syndrome Foundation National Office in Reston, VA. Many patients from the Washington D.C. Metro area attended along with their friends and family members for a morning of community building while raising awareness, and funds, for Sjögren's

The SSF staff not only helped organize the event, with a volunteer committee, but the staff also got involved to help reach our fundraising goal. The SSF's youngest staff members joined together and formed their own team, 'The Millennials' and had a friendly and spirited competition to see who could raise the most money – a challenge which resulted in one of the highest fundraising totals of any walk team this year!



"It was great to see our youngest staff join together to support Sjögren's patients by forming a walk team this past spring. Their commitment and compassion for Sjögren's patients goes beyond working for the SSF as was seen by their great success in raising funds and awareness among their family and friends."
– Steven Taylor, SSF CEO



The Millennial Team, SSF Staff Members from left to right: Matt Makara; Liz Fitzgerald; Alexis Beuchert.

To learn more about how to join us in conquering Sjögren's with our Walk for Sjögren's events, please visit: <http://events.sjogrens.org> or call Jessica Levy at (301) 530-4420 ext. 218





Team Sjögren's Goes Turkey!

Team Sjögren's

This Thanksgiving, we hope you will consider participating in your community Turkey Trot as a member of Team Sjögren's!

What a great way to start your day of giving thanks – by purchasing a Team Sjögren's Turkey Trot Kit and walking or running with others in your area, increasing awareness for Sjögren's and helping raise crucial funds for Sjögren's research.

With a **NEW T-shirt design**, you can represent Team Sjögren's in your community by purchasing a kit or by wearing it in a community Turkey Trot race.

You can find a local Turkey Trot by visiting www.active.com or in your local newspaper. If there isn't one in your area, consider creating your own Turkey Trot! Ask family and friends to join you for a morning walk in your neighborhood or at a nearby park on Thanksgiving morning while wearing your Team Sjögren's T-shirts!

Order your Team Sjögren's Turkey Trot Kit by calling 800-475-6473 or online at www.sjogrens.org.



NEW SHIRT



A Single Kit Includes: \$40

- Team Sjögren's T-shirt, with NEW Turkey Trot logo on the front!
- SSF Awareness Bracelet
- SSF Umbrella
- SSF Hat
- SSF Pin
- Certificate of Participation
- "What is Sjögren's?" Brochure

	Qty.	Size: S-2XL	Total
Team Sjögren's Turkey Trot T-Shirt	\$20 ea.		
Single Person Team Sjögren's Turkey Trot Kit	\$40 ea.		
Shipping and Handling:			
U.S. Mail: \$5 for first item + \$3 for each additional item			
Canada: \$14 for first item + \$3 for each additional item			
Overseas: \$22 for first item + \$3 for each additional item			
Total Amount Due			

**Mail to SSF: BB&T Bank • PO Box 890612 • Charlotte, NC 28289-0612
or Fax to: 301-530-4415**



Name _____
 Address _____
 City _____ State _____ Zip _____
 Telephone _____ E-Mail _____

Enclosed is a check or money order (in 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 _____ Security Code _____ Signature _____



in memoriam

In Memory of Alice Glupe

The Kelsey Family
BDO USA, LLP
Paul and Judy Bramfeld
Susan Bongiovanni
Kevin, Meg, Lauren and Ryan WrenGlupe

In Memory of Diane Guffey

Jim Guffey

In Memory of Florence Fox

Dana Chernock

In Memory of Harriett

Allan and Patti Fellner

In Memory of Heather Turney

Steve and Jody Jacobsen
Lisa Hale
Sallie Buchanan

In Memory of Helen A. Kinlan

Patrick V. Kinlan

In Memory of Kevin Gubbe

Jenny Schuff
Anthony and Kay Titus

In Memory of Helen Olshove

Don and Mary Schock

In Memory of Jane Gass

Thomas and Carol McCormick

In Memory of Joseph Bouchard

Joan Ruppenthal
Marie Natale and Paul Pickens
Knights of Columbus
Spike Robinson and Family
Allen and Barbara Ploof
Mary Lou and Charlie Breitzman
Fran and Dave Thomas

In Memory of Kathy Reiter Wolfe and Family

Sally and Craig Kiemy
Kathleen and Rick Smith
Tony and Joanne Breitzman
Mary O'Neil
Hila Robinson

In Memory of Karel Bretsch

The Smale Family
Kathleen and John Karkheck
Robert and Dorothy Wilkins

Kristen Schmitz
Karel A. Bretsch Living Trust Donors

Erwin and Theonia Amenda
Richard and Elizabeth Wallrath
Irmgard Spors
Joyce Mutz

In Memory of Pamela Morin

Leo and Theresa Griffin
Lynn Tucker
William and Claire LaCroix
W. Clark and Nancy Biehl
Jim and Joan Moy
Methacton co-workers and friends
Mr. and Mrs. Alain Dion
Mr. and Mrs. Michael Morin
Phyllis Morin
Linda and Wayne St. Peter
James and Margaret Schnellen
Perkiomen Valley Friends
and Neighbors Club
Roberta and Henry Kozak
Pat and Ken Lindenau

Kathy and Tom Carroll
James St. Peter and Jamie Lewinski
George and Mary Fleury
Robert and Suzanne Byers
Joyce Beaudry Bosworth
Kristine Furkey
Garry and Joyce Welch
Bob and Susan Murray
Cathy Miller

In Memory of Sandra Leanne Moran
Rick Brereton

In Memory of Wanda McClanahan

Gary and Rosemary Chappell

In Memory of Marybeth Lee

Cal U Financial Aid Office

In Memory of Nelly Thalheimer

Cohen Family (Deb, Mike and the Kids)
Mr. and Mrs. Jerome Robin
Martha Diamond and Family
Lisa and Mark Joseph
Julie and Harold Goldman
David and Debbie Herman



in honor

In Honor of Viktoria Schaub

Clemens Bruns Schaub Team

In Honor of Nancy Crabbe

Jane Stone

In Honor of Faye McCurry

Your daughter Kathy's friend, Vicki

In Honor of Jessica Levy

Patricia Scanlan

In Honor of Debby Wasserman

Wendy and Steve Robinson

In Honor of Chris Perry-Jacobs

Anonymous Facebook Donors

In Honor of Kristi Maguire

Christine Dennison



Shop Online for Sjögren's

Simplify your everyday shopping by having your merchandise delivered directly to you, while also supporting the SSF!

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!

Some of our partners include:




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



iGive.com offers exclusive deals with over 700 brand name stores you know and love, with a specified percentage of each purchase coming back to the SSF.



The Moisture Seekers
Sjögren's Syndrome Foundation Inc.
10701 Parkridge Blvd., Suite 170
Reston, VA 20191
Phone: 301-530-4420
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

Are you a Husband of Someone Living with Sjögren's?

The Sjögren's Syndrome Foundation knows how supporting and/or caring for someone with a chronic illness, like Sjögren's, can be very rewarding but it can also take a lot of out of you – physically and emotionally.

Please contact the Sjögren's Syndrome Foundation (SSF) at 301-530-4420 Ext. 203 or send an email to ssf@sjogrens.org and sign-up to receive specialized mailings, educational information, and notices about teleconference support group meetings for husbands of Sjögren's patients.

We know you will find the SSF's "Husbands Support Group" a great opportunity to connect, exchange helpful information and coping techniques with other husbands of Sjögren's patients – just like you!

Sign up today!

Teleconference Support Group Meetings
will start in January 2020!

