



FREQUENTLY ASKED QUESTIONS

ON CORONAVIRUS/COVID-19 and SJÖGREN'S

The Sjögren's Foundation is continuously working on ensuring that Sjögren's patients have the support and guidance they need during this challenging time. We hope the answers to these frequently asked questions will help give you a little more understanding and knowledge about Sjögren's and COVID-19.

1) What is Covid-19 and what are the symptoms?

COVID-19 is caused by a coronavirus called SARS-CoV-2. Coronaviruses are a large family of viruses that are common in people. However, Covid-19 is caused by a novel or new coronavirus, that has not been previously identified. The fact that Covid-19 is a new/novel strain allows it to spread more quickly among communities.

Common symptoms include fever, cough, and shortness of breath.

If you have any of these symptoms, you should CALL your doctor, local hospital or health clinic for advice and how best to be tested.

For additional information, consult the CDC's website:

<https://www.cdc.gov/coronavirus/2019-ncov/specific-groups/high-risk-complications.html#who-is-higher-risk>

2) Are there things I can be doing in advance to help build my immune system?

Working to make sure you are as healthy as possible is always good, especially in times when viruses are circulating in communities. Below are some healthy ways to build your immune system.

- Avoid smoking
- Include fruits and vegetables in your diet everyday
- Exercise regularly
- Maintain a healthy weight
- If you drink alcohol, drink only in moderation
- Get plenty of sleep to help recharge your immune system
- Talk with your healthcare professional about taking Vitamin C & Vitamin D supplements

3) Are patients with Sjögren's Immunocompromised/Immunosuppressed?

Not all Sjögren's patients have compromised immune systems. This specific risk factor is for those who regularly take drugs to suppress the immune system. Examples include prednisone, methylprednisolone, Imuran, azathioprine, methotrexate, leflunomide, Arava, CellCept, mycophenolate, Rituxan, cyclophosphamide.

Please note that hydroxychloroquine (Plaquenil) does NOT suppress your immune system and does not increase any risk for a more serious illness from COVID-19. However, all Sjögren's patients should still be diligent and be tested if symptoms become present.

4) What are Immunosuppressant's?

Immunosuppressants are a class of drugs that interfere with the function of cells composing the immune system. Drugs used in the chemotherapy of malignant disease and in the prevention of transplant rejection are generally immunosuppressive and occasionally are used to treat severe autoimmune disease.

Examples of immunosuppressant's that Sjögren's patients sometimes take include prednisone, methylprednisolone, Imuran, azathioprine, methotrexate, leflunomide, Arava, CellCept, mycophenolate, Rituxan, cyclophosphamide. If you take one of these drugs, your immune system is being suppressed and you should take extra precautions in preventing contracting COVID-19.

5) Is Hydroxychloroquine/Plaquenil an immunosuppressant and if not, why?

Hydroxychloroquine (HCQ) is an immunomodulatory drug. While this category of drugs includes immuno-suppressants, it also includes therapies that are not classified as such, including HCQ. Instead of suppressing the immune system, HCQ alters the way the immune system works. The drug reduces levels of type-1 interferon (IFN) and reduces interferon-stimulated gene expression (ISG). As such, it improves the way Sjögren's patients' immune system works and thereby improves Sjögren's symptoms. Other drugs such as corticosteroids work by suppressing an over-reactive immune system, but this is not the mode of action of HCQ. The FDA is looking into clinical trials with HCQ to see if it may improve the outcomes of people who are infected with the coronavirus that causes COVID-19.

6) If I have Sjögren's but not on any drugs that suppress my immune system, am I at higher risk of contracting COVID-19 than others?

As a Sjögren's patient, your risk is not necessarily higher (although there is research being done on this area) for getting the coronavirus than others, but if you do get diagnosed, you should let your physician know that you suffer from Sjögren's and that you may be at higher risk of complications from COVID-19.

Certain people are at a higher risk of developing serious complications from COVID-19. These include people:

- Over the age of 60
- Pregnant women
- People with serious chronic medical conditions such as heart disease, lung disease, diabetes, kidney conditions, or people with compromised immune systems

With this said, we do warn all Sjögren's patients to take extra precautions because of your chronic illness and because sound research has not been done on the level of risk for autoimmune diseases patients.

In addition, the Foundation is collaborating with one registry that is working with rheumatologists to track any COVID-19 diagnoses and progression within autoimmune disease patients (Sjögren's included). The data collected, we hope, will help us learn more about potential risk for autoimmune disease patients of contracting COVID-19.

7) Are there any extra precautions Sjögren's patients should be taking?

As the number of cases keep rising in the United States, the Foundation is encouraging all patients to consider taking all necessary precautions as outlined by the Centers for Disease Control and Prevention (CDC) to reduce your exposure. These precautions include:

- Wash your hands often with soap and water for at least 20 seconds
- Cover your cough/sneeze with a tissue or your elbow. Throw used tissues in trash
- Avoid touching your eyes, nose, and mouth with unwashed hands
- Wash hands each time before applying eye drops, dry mouth or dry skin products
- Avoid touching public surfaces
- Clean and disinfect frequently touched objects and surfaces
- Stay home when you are sick
- Avoid people who seem visibly sick
- Practice Social Distancing - Keep 6 feet between yourself and other people and stay home whenever possible
- Wear a cloth face covering when outside of your home in a community setting

8) Should I be wearing a mask?

The Sjögren's Foundation supports the CDC recommendation for cloth face coverings. "cloth face covering be worn whenever people are in a community setting, especially in situations where you may be near people. These settings include grocery stores and pharmacies. These face coverings are not a substitute for social distancing. Cloth face coverings are especially important to wear in public in areas of widespread COVID-19 illness."

Find more information regarding the CDC guidelines on face coverings by following this link <https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/diy-cloth-face-coverings.html>

9) If hydroxychloroquine/Plaquenil is being used to treat Covid-19, will the fact that I take it for my Sjögren's prevent me from getting the virus?

The use of Hydroxychloroquine (HCQ) has been anecdotally discussed as one of 10 drugs currently being investigated for the treatment of COVID-19. However, the CDC state's that there are "no approved drugs for dealing with the disease".

In addition, there are no trials yet investigating if being on HCQ will lessen your likelihood of contracting COVID-19. Thus, without peer-reviewed science, it cannot be said whether or not the daily use of HCQ in Sjögren's patients will prevent them from getting the disease or lessen their symptoms if they do contract it.

The Foundation has collaborated with one registry that is working with rheumatologists to track any COVID-19 diagnoses and progression with autoimmune disease patients (Sjögren's included). The data collected, we hope, will help us learn more about the potential risk of autoimmune disease patients contracting COVID-19 as well as any benefits of medications, etc.

10) What is the Sjögren's Foundation doing to address the shortage of Hydroxychloroquine/Plaquenil?

The Sjögren's Foundation has been active in addressing the shortage of Hydroxychloroquine (HCQ) for Sjögren's patients. We immediately wrote a letter to the FDA, to which they were very responsive and ensured us that they were working on the shortage.

In addition, we joined with other organizations, including the American College of Rheumatology to reach out to all state governors, insurance commissioners and boards of pharmacy to enlighten them on the shortage issue. The goal is to work towards increasing supply of HCQ, ensure no price gauging happens as well as ensure that refills for current autoimmune patients is a top priority.

The Foundation also heard from the U.S. President of Novartis Pharmaceuticals, one of the makers of Plaquenil. They announced that they are increasing production and donating 130 million doses of HCQ to the COVID-19 response, so as to free up other supply for autoimmune disease patients. Thanks to our relationship with PhRMA (Pharmaceutical Researchers & Manufacturers of America), the Foundation is in contact with other makers of Plaquenil, to ensure they understand the urgency of the supply shortage.

And finally, the Foundation has also reached out to all health insurance plans including Kaiser Permanente in California and others, that have been denying refills for the drug. This is unacceptable and the Foundation will continue to fight for our patient population.

11) Should I discontinue my immunosuppressant drugs?

The Sjögren's Foundation STRONGLY recommends against stopping the use of any drugs without a conversation with your physician, some drugs need explicit directions to be decreased slowly or have explicit directions in how to stop the medication. Stopping a medication without your physician's advice could be harmful and cause damage and increased disease activity.

12) If I have Sjögren's, should I be working or staying in quarantine?

The Sjögren's Foundation believes it is safest for Sjögren's patients to follow the CDC guidelines on social distancing. These include:

- Stay at least 6 feet (2 meters) from other people
- Do not gather in groups
- Stay out of crowded places and avoid mass gatherings

If you are required to work during the stay-at home orders, discuss potential alternative options with your employer where you may still work but remain socially distant.

In addition, always consider a telehealth appointment with your physician to discuss your various risk factors and if you should consider not working.

13) Should I cancel my Sjögren's related appointments?

Staying on top of your healthcare appointments is always important. We suggest you reach out to your providers in advance to discuss whether or not you should go into the office or if telehealth visits are an option for you.

14) If I am missing my regular dental check-ups during COVID-19 and I am worried about the long-term effect. What can I do to ensure I do not go backwards with my prevention of tooth decay?

To prevent tooth decay during this time, maintain your daily routine of brushing and flossing your teeth and once daily use of a topical fluoride prior to going to bed. During the COVID 19 pandemic, the sale of comfort foods such as popcorn, pretzels and potato chips has increased. Frequent consumption of carbohydrate or sugar containing snacks between meals is known to increase caries. So, if you must snack, do not let the snack debris sit on your teeth. Do not continuously sip on sugar containing or carbonated beverages throughout the day. Rinse out your mouth with water or mouthwash as soon as possible to get rid of the snack debris and help neutralize acid pH from beverages other than water and plain tea.

In summary: maintain meticulous oral hygiene, limit snacking and use a topical fluoride. Your dentist is likely available by phone or teleconference should there be specific individual concerns.

15) Should I be concerned about missing my regular eye care provider appointments, especially if I am on hydroxychloroquine due to retinal toxicity?

There has been concern about missing eye exam appointments for evaluating retinal toxicity while on hydroxychloroquine. Some eye care provider offices are open to check on this however if your eye doctor is not open, a few months delay in your exam should not put you at risk for problems. Consider rescheduling your appointment now by calling your eye care provider now to get an appointment booked for the future. Also, if you see any signs of any eye issues that concern you, reach out to your eye care provider who may be able to speak with you over the phone or have you come in for an emergency appointment if they feel it is necessary.

16) If I get diagnosed with Covid-19 what should I tell doctors about my Sjögren's?

Should you contract Covid-19, there are things you will want to do to alert your healthcare team about your Sjögren's.

Be prepared with the following: (Cont'd on next page)

- A list of your medications to provide to your healthcare team. It is important to let them know which medications you are already taking, especially is taking immunosuppressant's or hydroxychloroquine/Plaquenil.
- Information for your team of any reactions you have had to medications in the past, especially hydroxychloroquine/Plaquenil.
- Remind them of the lung complications that can occur with Sjögren's. You can provide them with the pulmonary patient education sheet available on our website or by clicking this link [Sjögren's Related Lung Disease Education Sheet](#)
- This sheet is also a helpful resource to provide to your healthcare team in case you need surgery or need to intubated: [Hospital Tips Education Sheet](#)