

Frequently Asked Questions (FAQ)

Scleroderma Foundation Michigan Chapter



Questions that appear on this page have been answered by SFMC's Medical Advisory Committee Member, Dr. Nina Ramessar. Dr. Ramessar went to the Medical School University of West Indies. She did her residency at SUNY Downtown Medical Center, where she also did her fellowship. She received her Board Certification from the American Board of Internal Medicine-Rheumatology. Dr. Ramessar practices at the Lakeland Rheumatology Clinic in St. Joseph, MI. The Michigan Chapter is honored to have her as part of our MAB and also to have her serve as a leader in the St. Joseph Support Group. To learn more about Dr. Ramessar you can view this short video. https://www.youtube.com/watch?time_continue=226&v=5uVqb3fGPXc

Thank you Dr. Ramessar for helping to educate the scleroderma community!

1. What is scleroderma?

This is an autoimmune disease which is very heterogeneous with skin tightening or fibrosis which can affect different parts of the body—the hands, feet, face, neck, extremities or trunk. It can be associated with organ involvement as well which is varied depending on how long the disease has been present and what type of autoantibody is present. Patients have Raynaud's phenomenon where there are color changes of the finger (or toes) with exposure to cold temperatures. A patient's digits may turn white, blue and then red.

2. What does the word scleroderma mean?

The word scleroderma is composed of two parts which are of Greek origin—"sclero" means hard and "derma" means skin.

3. Who can get scleroderma?

It is thought that patients who have certain types of genes, when exposed to certain viruses or environmental agents, their genes transform and thus start the process of creating the changes in the skin and the internal organs.

4. Is scleroderma contagious?

No. Scleroderma is not a contagious disease.

5. Is there a cure for scleroderma?

No, but there are ways to manage the different ways that the disease affects the different organs.

6. Is scleroderma inherited?

It can be inherited but this is mostly in rarer instances, and often it happens because of sudden genetic changes in patients.

7. Will scleroderma affect my internal organs?

Yes, it can affect the internal organs, which can include the heart, lung, stomach, esophagus, the entire gut (intestine) and the kidneys.

8. Can a scleroderma patient still become pregnant?

Yes, but you will need to be managed by a high risk obstetrician to ensure your wellbeing and the baby's.

9. Are there treatments for scleroderma?

There are treatments available for the different organs which are involved in Scleroderma. For Raynaud's phenomenon, there are different drugs which counteract the abnormal circulation and allow for less pain and discoloration. If there is lung involvement, there are certain immunosuppressants which can be used to try and halt more damage. For the skin tightening and fibrosis, there are similar immunosuppressant options which may work as well. There are currently many ongoing trials.

10. What is limited scleroderma?

This is a form of scleroderma where there is Raynaud's phenomenon along with skin tightening of the hands, face, feet and forearms. It is associated with acid reflux and other gastrointestinal complaints, a condition called pulmonary hypertension (where the pressure within the vessels of the lungs are higher than normal) and also interstitial lung disease (scarring and inflammation within the lung). Patients may also develop calcinosis, which are small calcium deposits are seen along the digits, and due to this and Raynaud's phenomenon, they may develop ulcers of the fingers. It is associated most with a specific antibody called anti-centromere.

11. What is diffused scleroderma?

This form of scleroderma is associated with Raynaud's as well, but also more skin thickening and fibrotic involvement of the trunk of the body. There are more noticeable changes of the nailbeds as well. Patients develop internal organ involvement earlier and there may be more heart, lung, gastrointestinal and kidney disease. It is associated with antibodies called anti-Scl-70 and anti-RNA polymerase .

12. What is CREST?

CREST stands for **C**alcinosis cutis (calcium deposits along the fingers), **R**aynaud phenomenon (discoloration and pain of the fingers and toes with cold exposure), **E**sophageal dysmotility (acid reflux and dry coughing), **S**clerodactyly (puffy and shiny hands which taper with time), and **T**elangiectasia (red spots made up of abnormal vessels on the face, neck ,chest and mouth) .

13. What is Raynaud's?

This can be a painful discoloration of the hands and feet with exposure to colder temperatures which may even include the refrigerator or even the colder lanes of the supermarket. The digits turn white first as the vessels tighten, then blue because there is no blood supply, and then red as the fingers start to get back blood flow.

14. What is the best way to manage my scleroderma?

Follow with your rheumatologist and other specialists closely so that organ involvement can be monitored for and managed aggressively. You will need to learn ways of avoiding situations where your Raynaud's will become more active, and also ways of controlling acid reflux symptoms with time. These issues need to be discussed with your providers at each visit.

15. How can I manage my fatigue?

- Continue with your routine as you see fit and continue to exercise and work within your limits.
- If you have heart or lung involvement, speak to your cardiologist or pulmonologist, who can recommend special rehab programs for specially tailored exercise programs which are available throughout the country.
- Make sure and mention the fatigue to your providers because it can be due to anemia (a low blood count) and this will need to be treated.

16. What types of physicians do scleroderma patients need to see for treatment?

Rheumatologists primarily see scleroderma patients but it depends on which organs are involved because you may need to see a pulmonologist, cardiologist, hand surgeon, or gastroenterologist.

17. What tests are common for scleroderma patients to have prescribed by their physician?

- Initially, you will have many blood tests to find out which antibody is present but after this initial assessment, you will not have to repeat these. It is done because the antibodies are associated with different internal organ involvement and your doctor will need to know how to monitor for these in the future.
- You will have less extensive routine blood work on a regular basis to ensure that there is development of anemia or kidney involvement from the disease. Monitoring will be done for the medications as well to ensure no adverse reaction.
- You will need an ECHO and pulmonary function tests every 6 to 12 months. You may also have to have a CT of the chest depending on what your physical exam reveals. Some patients may need a cardiac catheterization as well depending on if the lung and heart is involved.

18. Can I exercise and maintain a work-out schedule with scleroderma?

Yes, but this needs to be discussed with your specialists to ensure that it is safe and appropriate for you.

19. How can I tell my family and friends that I have scleroderma?

Have them come to one of your doctor's visits or join the support groups where family members are encouraged to attend, so that they can learn more from interacting and seeing other scleroderma patients.

20. I am overwhelmed about learning I have scleroderma, what can I do to cope better?

Join a support group so that you can learn from others who are in the same situation and to learn of ways to cope and visit the Scleroderma Foundation website and become a member.

21. My physician is challenging to communicate with, what is the best way to communicate with a medical professional?

There are many support groups throughout the country and these can be very beneficial and if you feel that your relationship with your physician not optimal, ask for a second opinion –that is your right.

22. Is there ever going to be a cure for scleroderma?

There is excellent research going on all over the United States and internationally and the hope is one day soon there will be a cure for scleroderma.

23. What is a clinical trial?

A clinical trial observes people in normal settings in order for researchers to gather information and to compare changes over time. Data can be collected through testing, verbal conversations, questionnaires, medical exams, or a combination of the above. Clinical trials are research based studies that help researchers find out if a new treatment is safe and effective in people. Some clinical trials help researchers gather data about a disease, help caregivers or support groups.

24. How can I learn more about clinical trials and if they are right for me?

To locate a clinical trial that is located near you and suits your specific needs go directly to this <https://clinicaltrials.gov/> link. Clinical Trials is a privately funded source and has information for trials all around the world.

25. How can I find a center of excellence to seek treatment for scleroderma?

By clicking on this link you can search the database and determine where the closest center of excellence is to where you reside.

http://www.scleroderma.org/site/PageServer?pagename=patients_centers#.W4fQ1c5KiUk