

**SCLERODERMA FOUNDATION CHAT
WEDNESDAY, NOVEMBER 13, 2002**

GUEST: Sampath Prahalad, M.D.

Welcome to the Scleroderma Foundation Chat Room!

ChatHost1 Welcome everyone to the Scleroderma Foundation Chat Room!!! Tonight our topic is Juvenile and Localized Scleroderma. We are lucky to have Sampath Prahalad, M.D. as our guest this evening. He is a professor, clinician, and researcher at the University of Utah School of Pediatrics, Division of Immunology and Rheumatology. He was a guest speaker at the National Conference and has assisted with our Salt Lake City Support Group. He is the co-investigator of the InterMountain States Database of Childhood Rheumatic Diseases. This program has enrolled 700 children to date. We are lucky to have his support and guidance.

ChatHost1 Welcome Dr. Prahalad

GUEST Thank you for inviting me. It is my pleasure to be participating in this chat.

kenimber My son is on Methotrexate. Is this the best for linear Scleroderma?

GUEST **Most pediatric rheumatologists use methotrexate for linear scleroderma.**

Tori How do you know when your child has juvenile scleroderma compared to regular scleroderma? My daughter's first scl-70 at the age of 16 was 53 and now at the age of 18 it is 76.

GUEST **The diagnosis of scleroderma is a combination of clinical and laboratory tests. In juvenile scleroderma, mostly we see localized scleroderma, or morphea. However, children can also have the systemic form. So the age by itself is not enough to differentiate between the two. Typically children with localized scleroderma do not have many antibodies other than ANA.**

Tori Thank you for that info that made sense. So if her ANA is 4.9 and her TPO is 347 along with her scl-70, what does that tell you?

GUEST **I would still want to know her clinical features. Does she have Raynaud's, and what kind of skin lesions does she have?**

Tori Yes, she has had Raynaud's for years and 2 yrs ago she had these sores that are round and raised and at first were raw and bleeding. Dr. Rawlings, at UCLA, did not know for sure if they went with the scleroderma. She has shiny skin and her muscles and joints hurt her a lot.

GUEST Pain in muscles and joints are common with many rheumatic conditions. With her labs and Raynaud's, it might suggest a systemic scleroderma rather than localized scleroderma. Sometimes it takes time to evolve.

Tori FYI, the sores are only on her feet. Her CPK has always been elevated. She has been tested for arthritis and lupus several times and they are always negative.

GUEST Sometimes it might take time for features to be more consistent. Make sure she is evaluated regularly. She might also see an adult rheumatologist, as they see more systemic scleroderma.

Tori She does see an adult rheumatologist. With her labs, would it be good for her to get into a research program and if so, where would you suggest? We live in southern CA.

GUEST Most research programs involve patients who can classify criteria for systemic sclerosis and if she does not have enough features to make a diagnosis, it might be hard to get into a study.

Tori What else is needed to make a diagnosis of SS?

GUEST Tori, without seeing her I cannot speculate. Typically they require the "typical sclerodermatous skin change" which includes tightness, thickening and non pitting induration as well as Raynaud's, and in addition, minor criteria such as capillary changes, GI involvement, Renal, cardiac or pulmonary involvement, etc.

Tori Thank you soooo much, we appreciate your input!

sclero Dr, an adult in my chapter emails me that she has linear scleroderma going into her eye area and wonders if there are any ophthalmologists who specialize in scleroderma, or with good knowledge of it in the US?

GUEST I am not aware of anyone right now. But I will be happy to enquire and pass on any names I find to your host.

sclero Is it true that morphea or some form of it can be treated with antibiotics?

GUEST Some cases of morphea-like lesions were once thought to be associated with Lyme disease and these might respond to antibiotics. Overall there have not been conclusive studies showing that antibiotics work in patients with morphea. D-penicillamine is a medicine that is used to treat morphea, but in spite of its name, it is not used as an antibiotic. (not to be confused with penicilline).

ChatHost1 I have heard that UVA treatments are proving effective for treating localized scleroderma. Have you had any experience with this therapy?

GUEST I have not personally had any experience with this. Fortunately, most of my patients have responded to methotrexate. However there are a few studies that seem to confirm this is helpful. I think it might become more widely used in the future, perhaps in combination with other modalities.

kenimber My son throws up when he knows we have given him Methotrexate and we have "hidden " it in root beer. He has figured this out and dumps the drink down the drain. We do not want to have to give him shots. Any suggestions?

GUEST That is a tough problem. Some children experience what we call "anticipatory nausea" with MTX. While there is no uniform treatment for this, the options are 1- Trying to split the dose into two over a 24 hour period; 2 - Sometimes we use a anti nausea medicine, called Zofran, a few hours before; or 3 - Methotrexate injections, which are not as bad as you might think. You may wish to talk to your pediatric rheumatologist.

Sadie I have had localized scleroderma since childhood (inactive at present). I am now thinking of starting a family. What are the risks of pregnancy and scleroderma (if any)? Any web sites/books where I could get more info?

GUEST To the best of my knowledge, if you have inactive localized scleroderma, no immediate risks comes to mind, although many autoimmune conditions may either flare or go quiescent during pregnancy. If I find any papers or articles, I shall pass it on to your host.

Sadie So there's no way of knowing?

GUEST Usually, the reported information is on things like Rheumatoid arthritis and SLE. Localized scleroderma is not reported with flares to my knowledge, but as I said, I will look it up and pass on the info to your host.

barrentine7 My mama is 72 and was diagnosed with systemic scleroderma 6 months ago. Are there medicines that can help her?

GUEST **There are different medications available for treating systemic scleroderma, but it depends on her particular symptoms and organ involvement.**

stermie I read or was told that a study showed dpen didn't work for scleroderma or at least showed results that there wasn't any difference between ones on high and low doses. Is this true? I was curious because you mentioned using it.

GUEST **You are correct. There was a study that showed no difference between high and low doses, however there was no control group who got placebo. So, there are some in the field that say you can't totally dismiss dpen, as the number of people who responded were supposed to be better than "historical controls". Most pediatric rheumatologists use MTX today as it is safer, and I think, more effective.**

barrentine7 We live in central Alabama. What would be the best way to find a Dr. that has treated systemic scleroderma?

GUEST **The arthritis foundation website would have names of rheumatologists. One way would be for your primary care doctor to talk to rheumatologists at the university hospital and find out people who might specialize in scleroderma.**

ChatHost1 We could help you find a doc in Alabama through our support group. There is also a university that conducts research in Alabama. Email me tomorrow sfinfo@scleroderma.org

ChatHost1 Dr. Prahalad, are there any multicenter studies regarding juvenile or localized scleroderma that we should be aware of?

GUEST **You mean ongoing studies or studies that have been done?**

ChatHost1 Ongoing. I would love to get the word out.

GUEST **I am not aware of any at this time. We have a new network of pediatric rheumatologists called CARRA that are coming up with ideas for multi-center, investigator initiated protocols. If I find anything out I will email you.**

ChatHost1 Thank you. In the mean time anyone looking for studies can visit www.clinicaltrials.gov.

ChatHost1 The Scleroderma Foundation would like to thank you for your time tonight. It was very informative. Thank you all for joining us. Watch our website for upcoming chats and our archives of transcripts. Goodnight! Thank you Dr. Prahalad. Goodnight everyone!

GUEST **You are welcome. It is my pleasure to join you. Good night all.**