

SCLERODERMA FOUNDATION CHAT
March 10, 2004

Welcome to the Scleroderma Foundation Chat Room!

Scleroderma Foundation's National Education and Research Director Carolyn Weller, RN is ChatHost1 and will answer any questions that anyone may have about the foundation, our upcoming conference, research, and treatments.

Sclero ChatHost, is there anything new and exciting in research? I get asked all the time in the chapter.

ChatHost1 There are few exciting things going on in the world of research particularly in clinical research. Several studies are currently enrolling patients to these studies in the hopes of finding more effective treatments for the complications of lung disease and digital ulcers. Information regarding these studies can be found on our website. Basic researchers are working very hard to determine what the cascade of events in the body is that causes fibroblasts to overproduce collagen.

Sclero So, there is some excitement in the area of symptoms and complications. How about knowing what the heck scleroderma is and curing it?

ChatHost1 The last studies about how the fibroblasts get turned on to overproduce collagen will hold much promise to help them target the fibroblasts with new therapies and figure out how to shut it down. The oral collagen study was another attempt to shut down this process through other means. Researchers sole focus is to develop new therapies to stop this disease! OK

ButterflyHope Is Bacterial overgrowth common in people with Scleroderma?

ChatHost1 Bacterial overgrowth can occur in persons that have involvement in their intestines. Food does not move through the way it should as the intestinal motility is slowed therefore causing the normal bacteria present in your bowel to flourish. It can be managed by antibiotics on short-term basis or by rotating to antibiotics.

Carrie Is there anything you can take to speed up intestinal motility?

ChatHost1 Carrie Reglan can be helpful to some, Propulsid used to be available on a compassionate usage by the pharmaceutical company but I understand that it is very hard to receive. For some Eerythromycin can help, and a new drug called Zelnorm for the more constipated variety can be helpful. Your Gastroenterologist should be able to determine what would be best for you.

Carrie **What does the Reglan do? I thought that slowed down the acid in your stomach?**

ChatHost1 Reglan relaxes the juncture between the stomach and the small intestine allowing food to flow from the stomach. It can help the acid reflux but also be helpful with small bowel motility.

Empresslisa **This is the first time I have ever interacted with someone about my disease (except for my doctor, Dr. Wiggly) I have not one friend where I live because I am so sick.**

ChatHost1 Empresslisa, what part of the country do you live in?

Empresslisa **I live in Southern New Jersey**

ChatHost1 You can find all of the contact information for the chapters in your area on our webpage. We have some great support groups in that area that would be very helpful to you. Please give Pat Johnsen a call at the Delaware Valley Chapter and she will get you connected.

Sclero **How many walkathons are there this year?**

ChatHost1 The last count I heard was 38, which is up from 25 last year. We have a few that have not confirmed as of this date. If anyone is interested please check out our website or contact your closest chapter.

Sally **I would like to know more about the walkathons in my area of Western PA**

ChatHost1 The closest walk in your area would be the walk in Youngstown OH area. If there is not a walk in your area and you are ambitious you could certainly plan one with the help of our development department.

Michelle I have been recently diagnosed, I have severe itching on my arms and legs. I have tried all types of creams and have had no success. Can anyone suggest a remedy for itching?

ButterflyHope I use a cream that I purchase from Wal-Mart called Queens Helene Butter and Cocoa Cream and it is great. A 32oz bottle sells for approximately \$1.99

ChatHost1 Has the doctor tried any antihistamines like Benadryl, Atarax?

Michelle I am Allergic to Benadryl

Carrie I use a mixture of baby lotion, Vaseline, and vitamin e cream and it's great

Empresslisa Shea Butter is excellent cream that can be purchased at Bath and Bodyworks- It's expensive, but worth every penny

ChatHost1 Antihistamines can be helpful to some. In severe cases a low dose of prednisone can be helpful. Please know that the itch will subside. The itch is associated with the active phase of the disease.

Michelle I have just started enbrel and have had six injections. So far it has not helped with the itch. How long will the itching last?

ChatHost1 Moisturizing is the key! One person told me some time ago that the sensitive skin Aveeno lotion with a few drops of cold pressed avocado oil mixed in is wonderful for controlling itch. Eucerin has a spray for itching. Time will help. As what is going on in the skin subsides the itching will abate

Carrie Have you heard of anyone having more joint pain while taking penicilamine? Also blisters?

ChatHost1 I haven't heard that but bear with me while I check for the common side effects... I do not see that as a common side effect but would certainly encourage you to address this symptom with your rheumatologist

Empresslisa My pinky fingers are very bent at the knuckles. Will they ever be straight again? And what can I do for them, they kill me?

ChatHost1 Talk to your doctor about a consult to an occupational therapist. It could be wonderful for you. The key is to always do the exercises, don't stop when the therapy stops.

Cherrymaster42 Does anyone know of something for the terrible fatigue?

ChatHost1 The key is to rest when you feel very fatigued. Take advantage of the good days but remember not to overdo it. Mild exercise such as yoga or tai chi can be helpful to increasing energy levels but always remember to talk to your doctor prior to starting any exercise program.

Sclero I would like to add that I have been dealing with this for ten years and fatigue has always been the most consistent and most annoying thing. The best thing I have found (and I know it's tough for some people to do) is to take control of your schedule. For me this means not working outside the home and allows you to roll with the punches- got a bad day? Then relax, got a good day then get some things done.

Empresslisa The sad thing is that My doctor, Dr. Wiggley gave me a script saying I need P.T. and or O.T. but nobody on the Jersey Shore will see me because I only have Medicaid for insurance. I just want to crawl under a rock and die, but know I am stronger than that.

ChatHost1 Empresslisa are you telling me that you cannot get therapy because you have Medicaid? Call the Delaware Valley Chapter, they have a social worker on staff part time that could be very helpful to you!!! Get what you need to be better.

Michele I'm on Enbrel, my doctor has just prescribed Methytrexate to go with it. Does anyone have experience with this combination?

Sclero Michelle, you may find more people who have experienced this in an arthritis group. I would suggest checking out the newsgroup alt.support.arthritis

ChatHost1 I can tell you that I know of many who do very well on Methotrexate, but am not familiar with this combo. Maybe your doctor could put you in touch with someone else that he has prescribed this combination therapy for as well.

Empresslisa

Is it normal to cry so easily as I do?

ChatHost1

Empress, you are grieving and overwhelmed. Yes it is normal. Please be sure to ask for help if you feel that you are depressed. That is also common and can be very easily managed with antidepressants. Support groups can be a wonderful place to find others that are experiencing the same feelings as yourself as well as helping you to not feel so isolated. I think that you need to seek that out. Even if it is just talking to someone else on the phone that you can relate to. Please do not keep yourself isolated. You are dealing with so much, seek out a support system. If there is something that we can do to help at the national level we can be reached at 800-722-4673. We would love to do what we can to help.

The Delaware Valley Chapter is having an educational seminar in April in Atlantic City. It would be a good chance for you to meet others as well as hear specialists in the fields of coping.

Sally

My ten-year-old daughter gets ulcers on her fingers and in her mouth. We are working with a pediatric rheumatologist and the ulcers are new since her last visit. What can she use for this?

ChatHost1

I would certainly give your Pediatric Rheumatologist a call and advise them as to this new symptom. Digital ulcers can be very debilitating due to the pain as well as impairing function of the hands. Every Doctor has their own special wound care treatment regimen that they recommend. The mouth ulcers could be from a medication, is she on Methotrexate? I believe that Methotrexate can cause mouth ulcerations. I would definitely give her doctor a call to see how to best intervene. In the meantime to give her pain relief from her mouth ulcers you could try oralbase gel or paste.

We will be starting a message board for the kids and parents in the near future, so keep a watch on our website. Additionally, if you have the means to attend the National Conference with her there will be a session on Juvenile Scleroderma as well as a chance for the parents and kids to get together and socialize. The information is on our website as well under 2004 Conference.

Cherrymaster42

Does anyone have problems with their hair falling out and problems with there teeth?

ChatHost1

Many experience problems with their teeth as a result of Sjogren's syndrome. The change in the PH in the mouth can cause an increase in cavities. Scleroderma can cause the bone in the jaw to become less causing teeth to become loose.

Julie

Has anyone have a liver function panel be high?

ChatHost1

Liver functions can be elevated due to some medications.

ChatHost1

Good night Empresslisa, Sally, Cherrymaster42, Carrie.
Next Chat will be the last Wednesday of the month. It will be an open chat, no guest, just you all chatting about whatever.
We hope to see you then!