

SCLERODERMA FOUNDATION CHAT April 14, 2004

Welcome to the Scleroderma Foundation Chat Room! Our chat guest tonight is Christine Pellerin of the MWW Group in Washington D.C. Christine advises the Scleroderma Foundation on advocacy strategy.

Sclero: I have been trying for months to get Ohio representatives and senators to co-sponsor the scleroderma bills, but most are not acting. What can I do besides reaching out with letters and phone calls?

Chathost1: If feasible, request a meeting in district offices and make sure that a constituent is involved. You can meet with the district staff; it doesn't necessarily have to be with the member. Send a letter to the editor appealing to the senator or representative to sign, or other articles in the paper highlighting the resolution. As many letters as possible from the Ohio constituents would be helpful as well.

Sclero: I have applied Dr. Mayes calculations of the prevalence of scleroderma to local census numbers and found that Ohio has about 12,000 people with scleroderma. Is this the kind of information the representatives will want?

Chathost1: Yes, particularly the senators. That is good information to provide. It shows how broad of an issue this is. It would be very helpful to generate as many letters as possible from those 12,000 people living with scleroderma. Sherrod Brown has signed on from Ohio as well as Stephanie Tubbs Jones,

Marcy Captor, Stephen Iatorrept, Tim Ryan and Ted Stickland. That is the House side of Ohio. Senator Dewine is usually very supportive of health issues and may be interested in this. It would be unusual for him to not be interested in something like this. MWW would be glad to follow up regarding this issue.

Sclero: I have sent my thanks to all the Ohio co-sponsors and asked them to encourage their fellows to also co-sponsor. I have written to all and even called the Ohio senators offices during Michigan (football) week requesting them to ask their Michigan counterparts regarding why they both have sponsored. We stood in the hallway last Capitol Hill Day and watched my hands turn colors with Dewine's health aid with great frustration turning up with nothing.

Chathost1: Sclero can you provide copies of the letters that the constituents have sent? MWW could follow up and it would be approaching it from several different fronts.

Chathost1: An orchestrated effort with many letters would get more attention for a senator as they have many more constituents and bigger issues. A letter from healthcare professionals could be helpful as well. Will you be at Capitol Hill Day Sclero?

Sclero: No, I will not be at Capitol Hill Day this year.
Are issues like health research not doing well on Capitol Hill due to the war issues? Like the NIH not getting the desired increase in funding?

Chathost1: The doubling of NIH is over and the other programs have not been given funding and other health care projects are now getting attention that were not getting attention during the NIH doubling. The war has moved other initiatives along more expeditiously than the NIH, etc.

Chathost1: Will there be another representative from Ohio?

Sclero: Not that I know of Chathost1.

Chathost2: Actually, I think there are two people coming from Ohio Sclero.

Sclero: The only ones I know of that were going have decided not to go.

Chathost2: Though at the moment, I can't think of whom exactly...

Sclero: What are the most important things before congress right now that are affecting us?

Chathost1: The Medicare modernization act and how that has been implemented. The demonstration project to get Tracleer included and covered by Medicare as a result of that legislation. The overall NIH funding trying to get scleroderma included in the ACE programs that is a 51 million dollar program, and trying to get dollars from the department of defense to grow the pot of scleroderma research dollars.

Not much legislatively in the health care arena is going to be moving in this. There was an organ donation legislation encouraging organ donation that passed and was signed President Bush last week. Many feel that is the only piece of health care legislation that will get passed this year. Although this is not specifically a scleroderma bill it will have an impact on scleroderma patients. The issue remains how to now fund this legislation.

Sclero: What else can we do to raise awareness about scleroderma and chronic illness besides going to Capitol Hill and actually talking to representative about certain bills?

Chathost1: Going to the media, op eds and letters to the editor. They read the clips in the newspapers every day. That is a wonderful way to increase awareness. If there are local chapter meetings or events that you could invite members to attend would further create an understanding of the disease to the member. Keep inviting them over and over. Always remember that if you go to Capitol Hill you are the expert on scleroderma. Take that passion and make them aware. Lots of volume is the key. They need to keep hearing it from back home or they won't be interested.

Sclero: Thanks.

Sclero: The event invite is a good idea since we have scleroderma walks planned this for this year.

Sclero: Denise, do you have any questions?

Denise: Do you know if there is anyone representing Florida on Capitol Hill Day?

Chathost2: Yes, we do have someone from Florida attending.

Denise: Great!

Chathost1: Denise, are there any issues that you can think of?

Denise: I just wish I were more educated on how to get the word out to the right people. This is all new to me.

Chathost1: Chapter and support groups are a good way to great a larger voice. Providing information to local physicians, nurses and government representatives can all be accomplished by using the resources of the foundation and the members of the group. Reach out to those around you Denise.

Sclero: Do you mean providing information on scleroderma to local physicians, nurses, etc?

Chathost1: Yes. Providing scleroderma *information* to the health professionals, and scleroderma *issues* to local government.

Sclero: Are we joining with other autoimmune organizations to get a larger voice on Capitol Hill?

Chathost2: Yes, we are working with several groups to get our message across. Last month the foundation was the host of NIAMS coalition day! The idea was to get many different non-profit organizations together to advocate on behalf of NIAMS.

Sclero: How many folks attended?

Chathost2: There were about 60 people in attendance.

Sclero: Wow, that sounds promising!

Chathost2: It was a great way to get information about NIAMS across to representatives and senators as well as to make a name for the foundation as an expert in the field of advocacy.

Chathost1: Continue to engage your members. It can be a frustrating process however; it will pay off if you continue on. Those that have success are relentless and the squeaky wheel always gets the grease. If you keep at it your persistence will be rewarded. You are a more effective voice that we often can be as you put a real face on this disease. It is important to give the members an understanding of the disease and you are the best people to do that.

Sclero: I think folks think advocacy is out of their reach, but the more practical ideas you give us, the more empowered we will be.

Denise: Thank you.

Chathost1: She hopes that this was helpful in that regard. Use the media, and the district staff to make the difference.

Sclero: We'll give it a try! Thanks!

Chathost1: Christine says thank you for having her and we hope that this was helpful!

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!