

Scleroderma Foundation Chat February 12, 2003

- chathost1** **Welcome! Good Evening Everyone Thanks for joining. Unfortunately, Our guest Jonathan Slade from MWW cannot join us this evening. We will have an open chat regarding advocacy. Gail Hardy our director of legislative affairs is on hand to assist in any questions. Does everyone know about House/Congress Resolution 30 (HCON RES 30)?**
- KAY What is that?
- chathost1** **HCON RES 30 is a bill expressing the sense of Congress regarding scleroderma.**
- sclero Yes. What's happening with that? Last I knew it was in committee.
- chathost1** **The Bill was introduced on Feb 5 on the House Side.**
- sclero What does it mean, "expressing the sense of congress?"
- chathost1** **We have 31 co-sponsors at the moment. Senator Gutierrez introduced the Bill into the house.**
- sclero Wow, that's great.
- chathost1** **It means that scleroderma will be recognized and acknowledge in congress.**
- PVDennis Is Gutierrez a senator or congressman? Is the 'sense of the congress' the same language that is used when they do stuff like 'national butter month'?
- KAY I think the rest of us acknowledged scleroderma a long time ago. Where have they been?
- chathost1** **The bill passed in the House last congress. We really need to work the Senate when it is introduced.**
- sclero Yeah, we've got to catch them up as usual.
- chathost1** **If you would like more information on the Bill it is on [Thomas.loc.gov](http://thomas.loc.gov) and type in "HCONRES 30" for the entire Bill.**

sclero Chat host 1, if it passed in the house last congress, why are we pushing it there again? Does it need to pass again?

chathost1 Yes even though it passed last year we have to introduce it again.

sclero Oh, okay.

PVDennis Once it passes (again), what benefits should we expect to see?

chathost1 The Bill has no funds attached to it. It is more a state of awareness. Let them know we are here and we need the funds to keep coming for more research!

PVDennis Do we have other initiatives that we're working in parallel? To get more \$\$?

chathost1 We are attending NIAMS Day. NIAMS funds research for scleroderma but, since they are a governmental agency, they cannot advocate for themselves, so we advocate for more funds for them (and us).

ChatHost2 What can we do at the local level to help with this effort?

chathost1 Try to meet with your local aids for your rep or senate and express the importance of the bill. I am also creating a manual on Advocacy to send out to everyone ASAP.

sclero A package for chapters or for individuals?

chathost1 For chapters and individuals. I am developing a CD on basic advocacy so everyone has a better understanding of the process in government.

sclero Cool!

tink Gail, Can you tell us a little about Capitol Hill Day in June?

chathost1 Capitol Hill is on June 24 . We will be going to the Capitol to meet with your senators and representatives. We are hoping to get as many people as possible to join us. We are hoping for 300!

sclero How will we prepare for the meetings, Gail?

chathost1 When you receive the conference registration there will be a place to check to let us know if you will be attending Capitol Hill and we will set up the appointments. I will have information packets ready for people once they register. This year we are hoping to have Senator Frist Speak at the National Conference as well.

ChatHost2 What issues can we address with our senators and legislators?

chathost1 I will also have information on where to go, who to meet with and the times to meet with them in the packet you will be receiving at check-in at the conference. We are also going to have an Advocacy table setup for any questions that might come up. And, yes, we will provide the bus trip to/from the Hotel. We are also going to be having a lunch at Capitol Hill. I am trying to secure the room as we speak.

sclero A lunch that day we are there, or earlier?

chathost1 The day we doing our visits. We will have morning visits and then break for lunch. After lunch we will have afternoon visit and then finish up by 3:30pm.

sclero Last year we did lunch on our own, but it would be cool to meet up with folks and compare notes.

ChatHost2 Are there specific issues we should raise during the visits?

chathost1 I am working with our Advocacy committee and our Firm in Washington to create talking points. I will be sending these out closer to our Capitol Hill Day.

sclero So, we'll have more specific thing to guide us this year?

ChatHost2 Is there anything that we can do locally prior to our visits in June?

chathost1 Yes, I will do my best to make it very smooth process. You can contact your local reps aide and let them know about the Bill and to please ask them to support it. You rarely get to speak to the Rep or Senator themselves but the Aides are the ones that express it to the rep or senator they work for.

sclero SO, it would be good to know who they are and expose them to info on scleroderma in advance?

chathost1 **Correct. I have everyone's Senators and Reps at the office on a spreadsheet, so if you don't know who they are please call me in the morning and I will be glad to help!**

sclero So, calling them locally or in DC about H Con Res 30 is okay? Is one better than another?

chathost1 **You would be better off calling DC. I have all the numbers.**

ChatHost2 I heard great news about the NIAMS allocation for scleroderma this year. How can we continue this trend?

chathost1 **We are working very closely with them. We are actually hosting NIAMS Day in 2004. This year, however, is going to be a tough, so when you talk to you rep/senators, express your concern about funding for NIH and the need for increased funding.**

sclero Would it be good to thank them for this increase?

chathost1 **Check out the website for more information on the NIH Health Budget that is in jeopardy. I posted the full story there. Always thank them, but also express concern for the coming year.**

sclero Wow. That is a concern - seems like we were just getting going.

chathost1 **I know ! We really need to push a lot this year with congress. Has anyone on the chat not attended our conference or Capitol Hill Day?**

ChatHost2 Phen, have you been to capital hill day?

phen No

ChatHost2 Phen, will you be attending our capital hill day this year?

phen I don't know.

sclero Hope so phen, its really neat.

ChatHost2 Do you attend the conference Phen? Please introduce yourself if you do as I recognize you from previous chats.

phen I haven't been to the conference.

ChatHost2 They are wonderful.

ChatHost2 Do you live close to DC?

phen From what I've heard, they are. I live in Colorado.

chathost1 **If you need any questions answered about the conference you are welcome to call and ask for Gail.**

phen Thanks. G'nite

tink good night everyone!!

chathost1 **Good night!**

sclero Nice save, Gail!!!!!!!!!!

jazzman good nite

sclero Night all!

ChatHost2 Nightie night