

Scleroderma Foundation Chat
Lauren Beeson & Samantha Murray
March 12, 2003

ChatHost1 Welcome everyone. Tonight we are fortunate to have with us two young ladies, Samantha and Lauren, who have done so much for the Scleroderma Foundation in regards to getting the word out about scleroderma to lawmakers on Capitol Hill as well as to the general population. Lauren has been hard at work for us for several years as our poster child and has now graciously consented to be our teen ambassador. She has participated in congressional hearings on Capitol Hill educating senators about the need for funding for scleroderma research. We are grateful for her commitment as well as her mother's support. We also have our new poster child Samantha Murray and her mother Stacey. We are excited about her taking on her new role as our poster child.

ChatHost1 We can open up questions to our guests. We are still awaiting Lauren and her mother, Marsi, to join us as they are having technical difficulties. So please bear with us. We can ask Samantha questions at this time.

sclero Samantha, how old were you when you were diagnosed?

samanthaM 4 years old

kfield How did you hear about the Foundation?

samanthaM searching the internet upon diagnosis

kfield What is the most important thing you have learned about SD?

samanthaM You can still be a normal eight your old with this disease... like play soccer, and ride my bike.

sclero It sounds like you're pretty active - how has the disease affected you, then?

samanthaM I get big cuts on the back of my legs, I broke my foot twice... my finger is bent, my skin is tight and uncomfortable... it takes me a little longer to learn and do some things... I get headaches, and have to get a shot every week.

ChatHost1 Samantha, what kind of a shot do you get

samanthaM **methotrexate**

sclero Do you get nauseated from the methotrexate?

samanthaM **Yes, sometimes.**

MrYeat Has your scleroderma affected you in school at all?

samanthaM **Yes... there is a boy in me class who bothers me and I have to have different teachers come in and take me out of class.**

kfield Are you going to the National Conference this June?

samanthaM **Yes, and I'm very excited.**

kfield Have you ever been to D.C.?

samanthaM **No.**

MrYeat Does your SD affect your family (brothers & sisters)?

samanthaM **It affects my family because they have to come 3 hours to New York with me, and when I'm sick they don't like it.**

ChatHost1 Samantha, do you have to have therapy for your scleroderma?

samanthaM **Yes...I get PT and OT at school and at home and in Boston.**

MrYeat Have you met any other kids with SD/Do you have a support group?

samanthaM **No, but I'm going to a meeting soon.**

MrYeat Have you ever been in newspaper or on the news?

samanthaM **Yes, 3 times but only once for scleroderma.**

MrYeat What newspaper?

samanthaM **The Boston Globe and the Foxboro Reporter.**

ChatHost1 Samantha, what is the most exciting thing for you about being the SF poster child?

samanthaM **Because I get to help people and feel better and know that this disease affects children too.**

Chathost2 Samantha, have you met or talked with Lauren yet?

samanthaM **Nope, but I can't wait.**

Chathost2 I'm sure she's looking forward to talking with you too.

kfield What are you looking forward to at the Conference?

samanthaM **I look forward to seeing other people with scleroderma... I've never been to Washington and it looks cool.**

sclero What can you do to make it easier for the newly diagnosed kid with scleroderma?

samanthaM **I would tell them that they can still do fun stuff and be normal and go to school.**

KarenY Why do you have to go all the way to New York for treatment?

samanthaM **Because we found a great doctor who takes good care of me... he's making me get better.**

Chathost2 Samantha - what would you like to be when you grow up?

samanthaM **I would like to be a doctor.**

sclero Where are you from? How far is it to travel to NY?

samanthaM **I am from Foxboro, Massachusetts and it takes three hours each way to go to New York.**

Chathost2 Samantha - what other plans are there for your job as poster child?

samanthaM **I'm going to be in some walks and a golf tournament and whatever else they need me to do.**

MrYeat What is your favorite color?

samanthaM **Every color of the rainbow... but mostly red.**

sclero Do you think you'll be outspoken about your scleroderma all your life?

samanthaM

Yes

KarenY

How has it been to work with the Foundation?

samanthaM

Awesome.

..... *Lauren joined*.....

samanthaM

Hi Lauren!

Lauren

Hi!

Lauren

Hello everyone!

ChatHost1

Lauren we would like to know how you feel about your new role for SF?

Lauren

Congratulations Samantha! I am very excited!

samanthaM

Thank you Lauren, I hope to follow in your footsteps and congrats too you!

Lauren

Thank you.

JessicaR

Were you nervous when the Foundation first asked you to be poster child?

Lauren

Who?

JessicaR

Both of you.

samanthaM

Lauren first.

Lauren

I was very nervous...but excited...it is a great opportunity.

samanthaM

Yes, very scared.

Lauren

Samantha you will do great!

JessicaR

I'm sure you will do a great job and follow in Lauren's footsteps!

samanthaM

Thank you both, I appreciate this opportunity.

kfield What did you enjoy the most about your role as poster child? What do you look forward to as Teen ambassador?

Lauren I enjoy being able to inform people about the disease... doing more to inform people about the disease.

ChatHost1 Lauren, What is the most exciting thing that happened as a result of you being poster child?

Lauren People saying that they have heard of scleroderma because of what we're doing.

Chathost2 Lauren - what advise would you give to Samantha?

Lauren Always be positive. Never let people get you down.

sclero Is it hard to stay positive? People can be rude or pushy...

Lauren Sometimes people are very rude ... it is very hard... but that is when you have the opportunity to tell them about scleroderma.

KarenY Samantha? How did you get involved with the Foundation? And then Lauren, how did you get involved way back when? Samantha, please go first.

samanthaM I first met people at the Randolph walkathon.

Lauren Ruth Greenspan told us to go to a chapter meeting. It was the best thing I did... getting involved.

JessicaR Lauren? Do people recognize you because of something you did for the Foundation?

Lauren Yes!

JessicaR What is that like?

Lauren People come up to me a lot... it is exciting. I feel like I am making a difference.

Chathost2 Samantha do you have any questions for Lauren?

samanthaM Do you like being part of the scleroderma foundation? Are you going to the conference in Washington? I can't wait to meet you!

Lauren Yes ... I have met a lot of wonderful and supportive people. Yes ... I can't wait to meet you too!

ChatHost1 Lauren what has been like going to Washington DC?

Lauren It has been wonderful...it is history in the making.

sclero Lauren and Samantha - what are the main things kids with scleroderma want or want to know?

Lauren If we'll find a cure in or lifetime.

samanthaM They want to know if they are going to get really sick and what can make you better.

Lauren Samantha, how do you feel about being the new poster child?

samanthaM I love it, it's like a dream come true because I can meet other people who have scleroderma and help others. How old were you when you were diagnosed?

Lauren 6

samanthaM How did you know something was wrong?

Lauren I had little white marks on my tummy...it was Morphea. I was wondering if Sammie had any pain... due to the disease?

samanthaM Yes... pain in my feet, in my stomach, headaches, pain on the back of my legs.

ChatHost1 I want to thank you both for joining us tonight!

samanthaM Your welcome, thank you!

ChatHost1 We are very lucky to have such special young ladies helping to get the word out about scleroderma. We are truly fortunate. You both should be very proud of yourselves.

Lauren You are welcome. Thank you for having us!

ChatHost1 We look forward to working with you in the future and please always remember that we are here for you.

Lauren **I am very proud of Samantha. Is the chat over?**

ChatHost1 Thank you everyone for joining our chat. Please join us for our next chat the last Wednesday of this month. This chat will be an open chat.

ChatHost1 Good night all!!!!

samanthaM **Good night to everyone, it's my bedtime!**

Lauren **Bye Everyone!**

samanthaM **Bye!**

Chathost2 Good night Samantha and Lauren!

Lauren **Good night Samantha!**

ChatHost1 Thank you Lauren!

samanthaM **Good night Lauren!**

ChatHost1 Sleep well Samantha!

samanthaM **You too!**