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***Understanding Scleroderma: Uncovering the Layers of a Chronic Disease***

Guests: Arthur Theodore, M.D., Martha Fisher, Marita Lanzilotta

Hosted by Andrew Schorr

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***Guest Arthur Theodore, M.D., of Boston University answers questions regarding symptoms, diagnosis, treatments, and current and upcoming clinical trials for patients with scleroderma. Also, two patients of Dr. Theodore's share their personal stories and how they live with scleroderma day by day, as well as listeners participate in the discussion over the phone and e-mail.***

**Andrew Schorr:**

Hello and thank you for joining us once again on Patient Power. Andrew Schorr broadcasting live from overcast Seattle but not rainy Seattle. You're going to meet three folks from Boston and the Boston area today. They are very excited for a couple of reasons. One is the Red Sox won, and now they're an empire, you know, and away they go, but the other is we're going to talk about a chronic condition that does not get talked about enough, and that is scleroderma, and you're going to hear about it. Now, I didn't know anything about it until I started reading in the celebrity magazines a number of years ago that a comedian and the guy on Full House, because my kids watched that on TV, Bob Saget. He was very concerned about it because his sister was afflicted by scleroderma and eventually died, and after that he did a made-for-TV movie about it, but since then you don't hear a lot. Now, the other day we discussed lupus. That too is a serious condition that affects people in lots of ways, an autoimmune condition; these conditions where your body turns on itself, so multiple sclerosis, rheumatoid arthritis, lupus, and yes, scleroderma. So, often when people are diagnosed with it, and it may take awhile, they've never heard of it, and what is it, and what that's going on in their body is the work of this illness, and what is it? How do you know? Because it affects different people different ways and also where do you get well-qualified care because it's not everywhere?

In a few minutes, we're going to meet a physician from Boston University who's totally dedicated to that and is an expert in scleroderma, but first let's meet two of his patients. So, first I'd like you to meet Martha Fisher. Martha joins us from Cambridge, Massachusetts, and you are a Red Sox fan, right Martha?



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**Martha Fisher:**

I do follow them, and I'm very thrilled with their success.

## **SOME SYMPTOMS OF SCLERODERMA AND GETTING DIAGNOSED**

### **Andrew Schorr:**

Okay, well you have to say that, but now, you have been living with scleroderma for what, 10 or 11 years?

### **Martha Fisher:**

Yes, although it wasn't diagnosed until about 6 years ago. It took awhile to get the diagnosis.

### **Andrew Schorr:**

What were the symptoms? I had somebody call me last night. They were calling about their kid, and they'd gone from doctor to doctor. Is that what happened to you? What were you suffering from, and why did it take so long to get diagnosed?

### **Martha Fisher:**

Scleroderma for me is primarily centered in the lungs, and I was continually having bouts of bronchitis. I had a chronic cough, and I pleaded with my doctor to help me find out what was wrong. Originally he thought it was environmental allergies and a form of asthma. It wasn't until several years later that it was finally pinned down to scleroderma.

### **Andrew Schorr:**

Okay. How has it affected you today after all these years? Forgive me, but it sounds like, you know, is it tough for your to breathe now?

### **Martha Fisher:**

Well, it is. I get short of breath fairly easily, and in fact nowadays talking for any extensive period of time will start me coughing or leave me short of breath. I used to be a professor or chemistry at a liberal arts college and would lecture for an hour or two at a time. I can no longer do that today, although thankfully my work doesn't require that of me anymore. I work at home doing editing work, but I get short of breath climbing a flight of steps or even walking at a fairly brisk pace, and I have to slow down in order to be able to breathe well.

### **Andrew Schorr:**

We're going to learn more about that. I want you to meet another patient who shares the same doctor you do at Boston University. That's Marita Lanzilotta. She's not too far away in Reading, Massachusetts. Marita, now you were diagnosed at age 40, about seven years ago, and I understand you had young kids at the time. How did scleroderma show up for you?

**Marita Lanzilotta:**

Scleroderma showed up for me in a different way than it did for Martha. My main complaint early on was severe joint pain and skin tightening, and I saw several doctors trying to determine what the source of this pain was. In several cases, I was told that it might actually be psychological pain, and after hearing that for three or four times, you know you start to wonder, but then I saw a rheumatologist up here on the north shore of Boston, and at my first visit after describing my symptoms to him, he hit the nail on the head. There was no testing involved at that point, but he put his finger on it right then and there, and at that point he referred me to Boston Medical Center.

**WHAT IS SCLERODERMA?**

**Andrew Schorr:**

Okay. Let's meet an expert from Boston Medical Center, your doctor and Martha's doctor, Dr. Arthur Theodore, who is Associate Professor of Medicine. He is Director of Medical Intensive Care, and he is Medical Director of Respiratory Therapy. You've got a lot of titles Dr. Theodore. I know you're very devoted to people with scleroderma. So, briefly before the break, what is scleroderma?

**Arthur Theodore:**

First of all, it's nice to be on with you, Andrew.

**Andrew Schorr:**

Thank you.

**Arthur Theodore:**

Scleroderma is really a condition that's defined as thickening of the skin from the Greek word "scleros" but it's more than that. It's a disorder that is systemic, hence the name, systemic sclerosis. So it's systemic in that it involves several other organs including the lungs, heart, gastrointestinal tract, skin, and of course the kidneys. The disorder is really unknown as to how it occurs. It can occur in anyone. It often tends to associate in families that have other immune conditions such as lupus, rheumatoid arthritis, and presumably it's some sort of genetic disorder where the genes become activated, again, by undetermined trigger that causes the disease to propagate.

**Andrew Schorr:**

Dr. Theodore, now I know that it can affect people in different ways, but these two ladies, their lungs are affected, and we heard with Martha about how it's difficult to take a deep breath or go up stairs. What's going on with the lungs with scleroderma?

**Arthur Theodore:**

The lungs are involved in approximately 70-80% of patients with scleroderma, and there are several different mechanisms by which this happens, the most common of which is where the lungs become fibrosed or sclerotic or scarred. This is really the same thing that you're seeing in the skin where the skin becomes thickened from an excess amount of collagen that's laid down in the skin. The same process occurs in the lungs, hence the name systemic sclerosis. When lungs become scarred and too much collagen is in them, then you can't expand them, and they can't exchange gas very well, and this kind of manifests itself in being short of breath with exertion at first and then progresses to the point where you're short of breath all the time.

**Andrew Schorr:**

We're going to take a break, Dr. Theodore, and learn a lot more from you, and I know we have many questions, and we invite people to call. We'll be right back with our live program on scleroderma on Patient Power right after this.

**LUNG AND OTHER ORGAN INVOLVEMENT WITH SCLERODERMA**

**Andrew Schorr:**

Thanks for joining us today on Patient Power. This is the only program live, day after day, from the patients perspective, because I'm an 11-year leukemia survivor and proud of it, I guess, really thanks to some great medical help, where we discuss chronic conditions and cancer and significant health issues day after day with some of the leading authorities in the world. Today we're joined by Dr. Arthur Theodore who is at Boston University Medical Center, and he specializes in particular in helping people with an autoimmune condition called scleroderma, and we're learning about that, and also two of his patients are joining us too from the Boston area; Martha Fisher in Cambridge and Marita Lanzilotta in Redding, Massachusetts, and we'll hear more from them later.

Dr. Theodore, I just want to go back. You described how in 70-80% of the patients it affects the lungs and the ability for those lungs to be flexible and exchange the gasses they need to for us to have proper respiration, but I know also that it can show up in different ways. We've heard about the skin. How else? Are people also very tired? I know with many autoimmune conditions, there's just a fatigue that goes with it too.

**Arthur Theodore:**

That is correct. In fact, some patients complain of such overwhelming fatigue that they are really unable to do much more than lie on a couch all day and barely perform the activities of daily living without any more specific complaints. I think in terms of the lung disease, I talked a little bit about the interstitial lung disease, the fibrosis, the scarring that happens, but there's a second lung disease also where the blood vessels

inside the lungs become involved and essentially drop out, and you end up with high blood pressure inside the lungs, which is termed pulmonary hypertension, and that is also a significant proportion of patients who end up with this condition as well, and the two conditions can overlap. You can have both kinds of lung disease.

The other real major involvement perhaps is involving the kidneys, and years ago in fact kidney involvement was fatal in many of our patients. It was the leading cause of death. Thankfully this condition now can be treated effectively with a very simple blood pressure medicine of the class of agents termed "ACE inhibitors."

**Andrew Schorr:**

Okay, we're going to hear more. We'll get into treatment as we go, and I get the impression, sir, that you're encouraged where we're headed with scleroderma because I know, and not that it's not a serious diagnosis and it's a variable for people, but the story from not that long ago was usually pretty bleak, wasn't it?

**Arthur Theodore:**

Yes, in fact before ACE inhibitors came out, once people developed renal crisis it was uniformly fatal, and that kind of brought to the issue now, since we can treat that, that the major cause of death is related to lung disease, and over the last 15 years we've made significant strides in treating this with still a very long way to go.

**Andrew Schorr:**

We're going to talk about where you are with treatments and where we are with research too. Let's take a call, and again people are welcome to call us at 877-711-5611 or 877-711-5211. I want to thank the Scleroderma Foundation for publicizing the program as well.

Patty, you are in Connecticut. Welcome to Patient Power.

**Patty:**

Thank you.

**Andrew Schorr:**

Where are you calling from in Connecticut, Patty?

**Patty:**

Torrington, the northwest corner.

**Andrew Schorr:**

I know where it is. Patty, are you living with scleroderma?

**Patty:**

Yes. I was diagnosed last year.

**Andrew Schorr:**

Oh my, okay. What's your question for Dr. Theodore or the ladies?

**Patty:**

My question is, last year I had a double heart catheter and was diagnosed with diastolic dysfunction, and I know that's not really common, and I was just wondering how that all plays into the scleroderma. I also have dermatomyositis, so I don't know which is causing what. How does it play into it?

**Andrew Schorr:**

Dr. Theodore, I know we can't do medicine over the airwaves exactly for specific cases.

**Arthur Theodore:**

We can talk about it generically of course.

**Andrew Schorr:**

Yes, please.

**Arthur Theodore:**

Scleroderma does involve the heart with the same process that involves the lungs and the skin. Again, collagen is a protein that gives the skin structure, and collagen is laid down abnormally in the heart tissue, and when this happens the heart becomes very stiff and can't relax or can't dilate. So certainly people who have systemic sclerosis that involves the heart, one of the types of heart disease we see is diastolic dysfunction where the heart can't dilate properly and fill with blood. I can't say that of course your condition is related to that because of many other...

**Andrew Schorr:**

Right. That's my question, and we had a similar discussion on the lupus program the other day, is so when you have an autoimmune condition that can show up in different ways for different people and affect different organs and systems, how do you know when it's your scleroderma is the bad actor or it's something else that should be treated in a different way? How do you know?

**Arthur Theodore:**

The most common reason for people to have diastolic dysfunction is hypertension, longstanding high blood pressure. So, some of it is historical. If you've had high blood pressure for a number of years, it's more likely to be that, but there's really no

definite way to exclude systemic sclerosis as a cause. Sometimes an echocardiogram can be suggestive, but the only real way to diagnosis it is to take a piece of heart tissue and look for findings that are more consistent with systemic sclerosis. Again, we generally don't do that clinically.

### **LIFE EXPECTANCY FOR PATIENTS WITH SCLERODERMA**

**Andrew Schorr:**

Okay. Thank you Patty. Here's a question we got in from Harry who's in Boston, Dr. Theodore. He says, my wife has recently been diagnosed with CREST scleroderma, and maybe you can help us understand what CREST scleroderma is. Can anything be said about the overall life expectancy of people with this diagnosis? I know it is variable, but maybe you can help us understand that for Harry.

**Arthur Theodore:**

Sure. So, CREST is defined by five different clinical criteria that really aren't used anymore. We generally term people with CREST syndrome to have what's called limited scleroderma. Limited being that it's confined to certain parts of the skin; the very ends of the forearms, hands, feet, face; rather than involving the body or the trunk per se, and there's really no way to predict how long someone is going to have the disease or live after they're diagnosed. There certainly are patients who have gone on for 25-30 years, and other patients that have very rapidly progressing disease where within a few years of diagnosis then they're dead.

**Andrew Schorr:**

Okay. Well, that's the whole thing is, it seems in talking with you, Dr. Theodore, and I know Martha and Marita will agree, that because of the variability and because of your growing understanding of the way it will affect different people and how some medications can help now, it would seem it makes sense to have a consultation with a scleroderma subspecialist. What would you say?

**Arthur Theodore:**

I agree with you. The disease is fairly rare. There are only about 10,000 or 20,000 cases or so per year, and most people just don't know how to deal with it since the treatment is fairly experimental, and I certainly would encourage anybody who has it to be referred to one of the many centers in the country where there is some experience treating it.

**Andrew Schorr:**

We'll be back more with out discussion of scleroderma and our conversation with Martha and Marita and also Dr. Arthur Theodore from Boston University Medical Center. It's all coming up as we continue on Patient Power right after this.

## **SUPPORT FOR PEOPLE WITH SCLERODERMA**

### **Andrew Schorr:**

We're talking about scleroderma, which is a fairly uncommon autoimmune condition, but when you take all of the autoimmune conditions together, it's not so uncommon you know, a few million people with rheumatoid arthritis, hundreds of thousands of people with multiple sclerosis, psoriasis, psoriatic arthritis, lupus we talked about just the other day, and then there's scleroderma, which is this hardening of the skin. We heard about it in the lungs. It can affect people in different ways, and the fatigue that goes with any of them.

So, Martha Fisher in Cambridge, when you were diagnosed with this, you hear about something that you really maybe never heard of, maybe didn't know anybody with it, and you go on and finally get an accurate diagnosis and you start treatments, but you still have to find support. What would you say to somebody who's newly diagnosed who is just bewildered and maybe depressed?

### **Martha Fisher:**

That's a great question. I think the first thing is to find out as much as possible about the condition. I did that by talking to my doctors, by reading a good book on the subject, by getting information from the Scleroderma Foundation, and also by looking at the medical literature. Secondly I would say that being in close touch with doctors and just keeping on top of my own personal symptoms and making sure that the doctors were clear about what was going on with me was important, and then developing a support network was another important thing. For me it's my husband and friends and my church.

### **Andrew Schorr:**

Good for you. Marita, what would you add to that? What's worked for you?

### **Marita Lanzilotta:**

I would expand that and say that make sure that you have a really good team of doctors involved in your care. I feel very blessed with the team of doctors that I have at Boston Medical Center. They all work together and that in itself gives me a great deal of confidence. In addition, my husband and I both have taken a really proactive role in my care and treatment, and again my team of doctors works with us, explains things to us very clearly, allows us to consider our own opinions and our own reservations, and are very willing to answer any and all questions that we have. Again, a good team of doctors is really the best thing that I can recommend.

## **TREATMENTS AND CLINICAL TRIALS FOR SCLERODERMA**

**Andrew Schorr:**

But with you in the lead, and that's what Patient Power is all about. Let's take a call. Do we have Amy in Orlando there?

**Amy:**

Yes you do.

**Andrew Schorr:**

Hi Amy. Are you living with scleroderma?

**Amy:**

Yes, I am.

**Andrew Schorr:**

What is your question?

**Amy:**

I have a question about stem cell. I received a Cytoxan treatment for about 20 months, but I've been told that stem cell is not an option since I have had the Cytoxan, and I was just wondering why.

**Andrew Schorr:**

Do you mean like a stem cell transplant?

**Amy:**

Yes.

**Andrew Schorr:**

Okay. Dr. Theodore, help us understand.

**Arthur Theodore:**

Sure. The stem cell transplant trial, which is called the SCOT trial standing for scleroderma cyclophosphamide or transplant compares cyclophosphamide to stem cell transplant, and therefore since one of the arms is cyclophosphamide, the exclusion criteria includes patients who were previously treated with that drug for more than really a small amount of time.

**Andrew Schorr:**

Okay, and I want to ask you about transplant. I know there's a physician at Northwestern who has been experimenting with transplant in multiple sclerosis, I think, or other things there. So, are you encouraged about transplant, or what do you think?

**Arthur Theodore:**

It's too early to say. The first reports of stem cell transplant being used for scleroderma lung disease I believe came out of Seattle actually several years ago.

**Andrew Schorr:**

Could be.

**Arthur Theodore:**

It was an uncontrolled study. It was just an anecdotal report that perhaps by doing this you would really give a long-term remission for systemic sclerosis. So, now there's the SCOT trial, and the SCOT trial is a trial that compares intravenous cyclophosphamide given monthly for a year to stem cell transplant. I'm quite encouraged actually by this approach since we think that the immune process that causes the body to attack itself resulting in scleroderma probably originates with immune cells produced by the bone marrow called T lymphocytes. I think so far we don't have any data from this trial. It's still ongoing, and I don't believe an interim analysis has been done, but I think we're all encouraged by this and hope that it will lead to a very good therapy.

**Andrew Schorr:**

Okay, we're going to talk about where we are in trials. Now, you mentioned, I know many patients receive actually a cancer drug I received for my leukemia, cyclophosphamide also known as Cytoxan, and from what I've understood in my own cases though, that can certainly affect your immune system long term. So, for me it was killing the cancer or helping people with their autoimmune disease in scleroderma, but is there another shoe to drop because I know you don't like to use that long term, although many people, including Martha and Marita and Amy who called, they've all received it.

**Arthur Theodore:**

Sure, and there are many problems with Cytoxan, the first of which is the dose and the time to use it. It's not clear to us how long someone should be on this drug to turn off the immune system that propagates this disease, and so we arbitrarily treat people for six months or twelve months or so in hopes that when we turn this process off it's turned off permanently and doesn't come back. The research so far with this shows that yes, we can turn off the process causing scleroderma lung disease with

cyclophosphamide but that after a year or two or three, the process resumes again, so the remission is short lived. Doses we use for scleroderma are much less than I'm sure you received for your chemotherapy.

**Andrew Schorr:**

Right.

**Arthur Theodore:**

It doesn't necessarily make it safer in the long run, but it does lessen the side effects in the short run.

### **PULMONARY HYPERTENSION IN SCLERODERMA PATIENTS**

**Andrew Schorr:**

Okay. Let's take an e-mail question we got from Amy in Ohio. She asks you, Dr. Theodore, could you please explain secondary pulmonary hypertension? Is it a lung complication or a heart complication, and can you catch it early by taking your blood pressure?

**Arthur Theodore:**

The answers are yes and no. You can't catch it by taking your blood pressure because it's pressure inside the lungs, which can only be measured directly by putting a catheter through the heart into the lungs and hooking it up to a pressure device. Generally the symptoms that you get from pulmonary hypertension related to scleroderma are shortness of breath with exertion. That's very indistinguishable from any other kind of shortness of breath you can get with exerting yourself. There are tests, namely the echocardiogram, which is a noninvasive test that can estimate the blood pressure inside the lungs. It is a disease of the lung blood vessels itself and does affect the heart if it progresses, but it's not an easy problem to diagnose. Again, I do recommend people to monitor their shortness of breath and should it progress to notify their physician so that some of these tests could be done and treat it earlier. People do better, but it doesn't necessarily change prognosis in the long run.

### **REMISSION IN SCLERODERMA**

**Andrew Schorr:**

Here's a question we got in from Brenda in North Carolina, and she writes, I have been diagnosed with MCTD, and you'll have to help us understand what that is, and the scleroderma is affecting my fingers, feet, and lungs. Is the disease likely to go into remission even if it's advanced?

**Arthur Theodore:**

MCDT stands for mixed connective tissue disease, and like all these other diseases, it's defined differently in different people, but essentially it's a combination of rheumatoid arthritis, lupus, and scleroderma in different aspects. It is diagnosed by a certain type of antibody that people develop. Yes, the disease does involve the lungs. Thankfully it tends to be more benign in terms of its progression in that you may have some lung involvement that may give you symptoms and limit you, but it's unlikely to progress and be a terminal condition. There's no known treatment for this either.

**PROGNOSIS FACTORS AND GENETIC CONNECTIONS**

**Andrew Schorr:**

Dr. Theodore, let's talk about treatments; well, first of all, maybe prognosis because you used that term. So if the disease or a constellation of diseases that can include scleroderma vary in so many people, how do you know what your prognosis is? Do you have a test? Do you look at genetic abnormalities? What do you look at to say Mr. Smith or Mrs. Jones, here's what we think lies ahead for you? How do you do that?

**Arthur Theodore:**

Some of the antibody tests are helpful; at least in terms of predicting what organ may or may not be involved. The anti-Scl-70 antibody occurs in about 30% of patients that have the diffuse form of scleroderma and tends to be more associated with the interstitial type of lung disease. On the contrary, people who have anticentromere antibody, which occurs more in the limited form perhaps 70-80% of the time, would be much more likely to predict pulmonary hypertension as a lung involvement, but in spite of being able to predict what organ may or may not be involved, it's really impossible to predict anybody's prognosis. Certainly there are people who present with very fulminant and rapidly progressive disease, and as you would expect, those patients tend to do less well than people that just have symptoms of a runny nose or a little skin thickening for 10, 15, or 20 years or so.

**Andrew Schorr:**

Well, we're all on a journey. Nobody knows what's going to get us in the end, but you know, you worry about this; not just for ourselves but also for our children. So, do we see scleroderma in families? Or when you look at the whole family do you say, well we see autoimmune conditions in family?

**Arthur Theodore:**

Yes. In fact, a very large percent of patients with scleroderma have a first-degree relative; parent, grandparent, sibling, or cousin; who has some other autoimmune disease whether it be lupus or rheumatoid arthritis or dermatomyositis or even diseases like sarcoid or psoriasis. But there's no way to predict who in a family is

going to get it from someone else's gene makeup because we just don't have the knowledge yet. It does not appear that it is a specific gene, for example like cystic fibrosis, that's involved. Rather it's a series or set of genes that need to be activated that cause the disease.

## **FUTURE CLINICAL TRIALS**

### **Andrew Schorr:**

Dr. Theodore, so where are we with research? So, Cytoxan or cyclophosphamide is not the greatest drug, but it's helpful in the short term. You're doing research as you said and stem cell transplants. What are some other studies going on at BU that you're encouraged about and that maybe people might want to consider participating in?

### **Arthur Theodore:**

The next national study is what's going to be called scleroderma lung study II, which is a followup for the first Cytoxan study, and this study which should be up and going within the next year or so compares cyclophosphamide given for a year to a drug called mycophenolate or CellCept given for two years. This is a comparison trial with a drug that now has been shown to be somewhat effective against a different drug, which we hope will be more promising and has less side effects. So that's one trial that will be up and coming. I've already mentioned the SCOT trial, which is currently ongoing, and it's really limited to patients who have rapidly progressive systemic sclerosis with extensive skin involvement and has a lot of exclusion criteria which include not having been treated with Cytoxan in the past.

Finally, there are two other trials that I know of that are at least clinical involving the lungs. Both are sponsored by drug companies involving the use of antibodies, human monoclonal antibodies, against cytokines, and cytokines are proteins made by lymphocytes, the cells that kind of mediate this process, using antibodies to counteract these cytokines, which are present in the disease process in the lungs. These are still probably one to two to three years away.

### **Andrew Schorr:**

I just want to make my little Patient Power speech for considering clinical trials. I am an 11-year leukemia survivor. I consulted with specialist in my illness, which was 2,000 miles from my home, but as we say with scleroderma, go where there are experts such as Dr. Theodore at Boston Medical Center, and then consider a clinical trial. I was patient #60 in a phase II trial, and I am talking to you here today. Most people get what I got years ago, so it doesn't always work out that way, but certainly consider it.

## **IS SURGERY AN OPTION?**

Dr. Theodore, here's a question we got from Mary Beth in Illinois. She writes, I have diffuse scleroderma, and my main problem is the fast and strong stiffness of the muscle and joints. I've tried many kinds of steroids, oral and IV and intramuscular, but there was not much good. So, do you have any other treatments for this problem, and is there any kind of surgery for her hands and her fingers to improve their movement?

### **Arthur Theodore:**

Because the disease involves the skin, generally the answer to surgery is no. There are conditions where a tendon, for example, may be entrapped where a tendon release procedure might be helpful, but generally because of the blood flow characteristics of the extremities in scleroderma, we don't like to operate because the healing is so poor. In terms of relief of symptoms for extremities or joints and things, generally as you know steroids are the mainstay of treatment. Cytoxan has been shown perhaps to help the skin involvement, but to my knowledge it really hasn't been shown to help the joint involvement and the pain that people get from these things nearly as much as more common treatments like treatment with nonsteroidal drugs like Motrin, etc. tend to give.

## **LIVING WITH SCLERODERMA**

### **Andrew Schorr:**

So I have a question for Martha. Martha, how do you approach every day now? So, you know, you changed the work you do; nobody knows what lies ahead; you have your support network. So, I know you told me during one of the breaks the sun is shining there in Cambridge today. How do you approach the day living with a serious chronic condition with maybe an uncertain future?

### **Martha Fisher:**

Well, I do have to ask for help. My husband helps a great deal with doing things that I'm not able to do. I also ask God for help every day, and prayer and the help of my friends and their prayers are a great help to me.

### **Andrew Schorr:**

Yes. Now Marita, how old are your kids now?

### **Marita Lanzilotta:**

I have an 8-year-old and an 11-year-old.

**Andrew Schorr:**

Okay. That requires a lot of energy. I know, I have three kids.

**Marita Lanzilotta:**

Indeed.

**Andrew Schorr:**

So how do you do that? How is your scleroderma affecting you now, and how do you do that? Or do you ask for help like Martha does?

**Marita Lanzilotta:**

Day to day I'm able to do the running around and the carpooling and those sorts of things that need to be done. From time to time I do have periods where I do need help, and I have a fabulous group of friends and neighbors who are always available to me. My husband as well is very flexible in his work and is able to help me when necessary. I also find resting is key as well. If I'm feeling the least bit tired; if I just sit and rest for 15-20 minutes, that definitely gives me the edge to get through the rest of the day.

**Andrew Schorr:**

That's good advice. That's good advice for all of us in America. We're all probably moving too fast I think sometimes.

Dr. Theodore, I'm just going to get another comment from you, sir. So you're our barometer because you specialize in this, and you have patients like Martha and Marita who you've been helping. So are you optimistic, sir, that with like, you know, we've developed these biologic therapies for rheumatoid arthritis and biologic medicines to slow the progression of multiple sclerosis or psoriasis. What about for scleroderma?

**Arthur Theodore:**

I think that at some point we'll have enough of an understanding of the disease to be able to treat it effectively. Realistically, that time is a long way off. Right now we're using sledges to kill ants in that we have such a poor understanding of what causes the disease, we're only kind of treating the symptoms or the progression of the disease with our treatments. So, in the long-term I think yes, we will be successful. I think that time is probably years away.

**Andrew Schorr:**

Okay. We are partners with you, sir, and I mentioned about clinical trials. We all have to work together in that way as far as if a clinical trial is right for you, partnering with a researcher like Dr. Theodore at Boston University. The other thing is speaking out,

and Martha and Marita, I want to thank you for speaking out because, again, it's not a household word. I want to see, in just the brief time we have left, let's take a quick call from Alli who's in Atlanta. Alli, are you still there?

**Alli:**

I am.

**Andrew Schorr:**

Go right ahead. We'll try to get your question quickly.

**Alli:**

Okay. I have \_\_\_\_\_ sclerosis with interstitial lung disease, and I'm wondering how doctors determine whether to treat it with Cytoxan or CellCept. I am currently on CellCept.

**Andrew Schorr:**

Dr. Theodore?

**Arthur Theodore:**

That's a very good question. Generally when patients present and are found to have active interstitial lung disease, we offer patients choices based upon what we know. You know, we know that Cytoxan does help for a while. We know it's not a long-term thing. We don't know really much about mycophenolate. These are uncontrolled studies that have shown it to be helpful. The real decision is the patients given the symptoms, what can happen, what can progress, what we know. It's up to the patient to opt for one form of treatment or another knowing that probably none of these choices are great. I do encourage people as Mr. Schorr mentioned to consider clinical trials. We can certainly help. These are designed to help patients and are based on scientific evidence that one treatment or another is likely to be beneficial.

**Andrew Schorr:**

Right. We're going to have to go. Alli, I hope that's helpful. Dr. Arthur Theodore at Boston University School of Medicine and Boston Medical Center, thanks for your devotion to this. Martha Fisher in Cambridge and Marita Lanzilotta in Reading, Massachusetts, thank you. All the best to you. And also I want to mention, please take a look at [scleroderma.org](http://scleroderma.org) and the Scleroderma Foundation. They have packets for you, free, that can help, and you might also want to check out the International Scleroderma Foundation. Their web site is [sclero.org](http://sclero.org).



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As always, knowledge can be the best medicine of all. Tune in to Patient Power again. The replay will be posted soon on [patientpower.info](http://patientpower.info). Have a great day and as always, remember, as I said, knowledge can be the best medicine of all and a good medical team.

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