Leading Rheumatologist Gives 6 Reasons to Have Hope About Scleroderma & Why Research is the Answer

“I kind of fell into this,” Dr. Fischer told me.

You wouldn’t know it by looking at the Doctor of the Year award sitting on his desk. He received it in 2014 from the Scleroderma Foundation at the National Patient Education Conference.

Despite the unexpected journey, Dr. Fischer is now a Rheumatologist, researcher, and associate professor at the University of Colorado School of Medicine here in Colorado working every day to help his scleroderma patients live better and longer. He’s also a member of the Scleroderma Foundation’s medical advisory board and a faculty member for the Foundation’s Continuing Medical Education/Continuing Nursing Education program.

We sat down in his office on the Anschutz Campus in Aurora to discuss where we’ve come in the fight and where we’re going. If there’s anyone to give us perspective, Dr. Fischer is the guy, the guru, the expert.
What I came away with is 6 distinct reasons to have hope:

1. There is More Research Being Conducted Than Ever Before

“When I was a resident, this is what I knew about scleroderma: You wanted no part of it; it was rare; it was devastating; and nothing works. The saying in scleroderma was ‘No drug has been proven to be a failure until it was tried in scleroderma.’”

That was at the turn of the century. And now?

There are new local, national, and international research efforts popping up. Some of them are the largest studies ever done on the disease looking at responses to new treatments and possible causes.

“Unheard of numbers,” Dr. Fischer said passionately. “Unheard of support across an international network.”

It takes time, but there is momentum.

2. Scleroderma Treatments May Have Been The Butt of Jokes But Now They’re Saving Lives

Dr. Fischer went down the list. From basically no signs of hope, there are now improvements in just about every area.

Cellcept (mycophenolate mofetil), for one, is a step forward. Ten years ago it wasn’t used with scleroderma, but in part because of research published by Dr. Fischer and his colleagues, it is now the most commonly prescribed drug for the treatment of scleroderma lung fibrosis and skin thickening. Pulmonary hypertension used to be a 2½ year life sentence, but now has 15 therapies proven to be effective. Kidney failure, another one, used to be uniformly lethal but advancements have taken it out of the top five causes of fatality.

“That’s where research can really impact patients.”
With more research, more treatments can make their way to patients.

“There are tons of pipeline drugs – meaning drugs that are working in the lab, working in animal models that are now being developed on humans.”

3. Doctors are Better Educated on Scleroderma’s Subtle Symptoms

While scleroderma isn’t new, for a long time it was thought there had to be skin involvement for a definitive diagnosis. Now we know that’s not true.

Dr. Fischer and the Scleroderma Foundation are making that known to doctors across fields – primary care, pulmonology, cardiology, gastroenterology, etc. – so patients aren’t getting lost wading through ineffective treatments in the wrong doctor’s office.

When the correct diagnosis is made, and made quicker, we know patients respond better to the treatments prescribed.

4. The Scleroderma Foundation is Stronger Than Ever

Dr. Fischer has been involved with the Scleroderma Foundation for about 10 years and has seen impressive changes.

“The Scleroderma Foundation is more organized, more put together with a broader network and is getting more funding, now than ever before.”

And that’s vital. When a patient is diagnosed with the disease, even if they have a great doctor, there is a lot of mystery and a lot of fear. The Foundation can step in.

“You don’t know where to turn,” Dr. Fischer explained. “You can’t go online. Your family has no clue. You have to go to people at the Scleroderma Foundation and people who have the disease – people who understand and can help with the shock.”

It’s a good sign and we’re happy Dr. Fischer noticed, but we want to do more.
5. The Medical Community Has New Energy to Help Scleroderma Patients

We’re a far cry from when Dr. Fischer was a resident discussing how futile treatments were in scleroderma. Now, Dr. Fischer says young rheumatologists are seeing the excitement of the research and scleroderma as an opportunity to be on the cutting edge.

“We have all these people dedicated to lupus, all these people dedicated to rheumatoid, all these people involved with other autoimmune diseases. But now, with scleroderma, people are seeing the opportunities and the excitement related to all the research there. They’re thinking, ‘let me delve into that.’”

The Scleroderma Foundation is looking to encourage that excitement with a new program pairing established researchers with up-and-coming doctors interested in investigating new treatments.

6. The Strength of Scleroderma Patients
Last and *certainly* not least.

The staff at the Scleroderma Foundation and Dr. Fischer see it all the time: a willingness to endure, a determination to not give up. Hopefully you’ve heard about that in [Lauren's determination](#) and [Sandee's leadership](#) the last couple weeks.

These are real signs of hope. But there is work to be done.

“We’re looking for treatments that really affect the way people feel, the way organs are involved, where we can minimize the damage, and help people live a healthier lifestyle and a longer lifestyle. Those are realistic outcomes and those don’t happen without research."

Colorado Gives Day is an opportunity to help us take the next step. It won’t happen all at once, but it won’t happen at all without your help.

*Schedule your #COGivesDay donation now* and *get in touch with us* to discover how you can be more involved. Thank you!

*Written by Kelley Birschbach, GoTellMarketing*