

Transcript Details

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What IPF Really Means: Discussions with Caregivers, Patients, & Healthcare Providers

Announcer:

This is Conference Coverage on ReachMD. The following activity includes excerpts of interviews with attendees at the 2017 Pulmonary Fibrosis Foundation Summit in Nashville, Tennessee. This activity was provided in partnership with Global Academy for Medical Education.

Here's your host, Dr. Shira Johnson.

Dr. Johnson:

The ReachMD team and I recently spoke with some of the patients, caregivers, and healthcare providers taking part in the 2017 PFF summit. They told us about their experiences with idiopathic pulmonary fibrosis, IPF, which is a challenging disease, in part because diagnosis can be delayed.

Our discussion began with Sheila Clemons, who is living with IPF, and Kim Gardner, a caregiver.

Sheila Clemons:

Well, I live in Cullman, Alabama, and I went to a local pulmonologist for about a year, and he kept thinking I had lupus. They never did think I had pulmonary fibrosis. And they done a biopsy on me then, and they still didn't determine what it was, so I got a second opinion and ended up at UAB in Birmingham, and Dr. Keith Wille is my doctor, and he treated me for about another year, and then he finally said, "We're going to have to do another lung biopsy," so they did another lung biopsy, and that's how they determined. So, it was 2 years before I got diagnosed before I found out I had pulmonary fibrosis, but I was already on oxygen before I even found out.

Kim Gardner:

I think the number one thing I would like to say to the providers is, "Listen to your patients and listen to their families." You know, it took a long time for my mom to get diagnosed, and it took a major exacerbation and a lung biopsy, and we almost lost her in that process, and it had been going on for years. She had kept going to doctors saying, "Something is wrong, something is wrong, something is wrong," and I feel like it was just taking a long time to get it figured out. And then we started putting 2-and-2 together with her diagnosis and realized it's exactly what my grandmother had, and since then we've started making more and more family connections.

Dr. Johnson:

Next, we were joined by DeAnne Todd, a caregiver, John Dominguez, lung transplant recipient and support group leader, and Carol Bair, clinical coordinator for an Interstitial Lung Disease Program.

They spoke about recent and future advances in the treatment of IPF.

DeAnne Todd:

So, back in that time transplant really was his only option, but now there are these drug therapies that have been approved and learning about some drug therapies that are in the works, so I think that there's a lot of hope for pulmonary fibrosis patients.

John Dominguez:

There's a lot of people in the same boat that have gone through the same misdiagnoses, and there's a lot of things on the horizon that

look promising. And so far we only have 2 drugs to fight this disease, and maybe in the next couple of years they'll come up with something else. And one of the things I follow real closely is the stem cell therapy. There's no FDA-approved stem cell therapy for IPF, but maybe that looks like the most promising, at least to me, of therapies that would be able to take care of IPF.

Carol Bair:

The one I just went to regarding future research in stem cell therapy, so that will hopefully, I think, keep people informed, and maybe there's a new therapy out there that we don't know about.

Dr. Johnson:

Next, caregivers DeAnne Todd and Denise Breeden shared their thoughts about the importance of IPF support groups.

DeAnne Todd:

Once my father got his transplant I just realized that there are so many people that needed to come to the support group meetings and get the support they needed, both patients and caregivers, and so I became actively involved in the support group and helping in any way I could with other patients. And since that time our original support group founder has passed away from pulmonary fibrosis, and so now I'm taking a more active role. And this was my first opportunity to come to the summit, and I'm here to learn.

Denise Breeden:

Right, that's what we tell everybody. Don't just stop. And I think everybody that's come to the support group that knows nothing about the disease, that's what they say. They come in and they feel like we did. We learned so much, and it gives them hope that it's not just this death sentence and there's just nothing you can do and you might as well just go home and crawl in a hole. It's not like that at all. And so people feel so relieved. You can just see it when they walk out of the meeting, and just to have that support, it is wonderful.

Dr. Johnson:

We also asked caregiver DeAnne Todd, and IPF patients Peter Mulliner and Sheila Clemons about their advice for others who are dealing with IPF.

DeAnne Todd:

Definitely, information. Knowledge is power, and so the more knowledge you can gain about the disease itself and about things that you can do as a caregiver or your loved one can do as a patient to improve their quality of life.

Peter Mulliner:

Ask the doctor the questions. Think about what it is that's important to you and tell the doctor what it is that's important to you so that he knows how to help you make your life better, be more effective. We're stuck with this disease. There's no getting around it, so accept that and then say, "Okay, what can I do to keep my quality of life? Doctor, what is it that I can do that you can help me with so that I can continue to do what I love for as long as possible?" Ask the doctor the questions. Get them to respond to you. Get them to point you in the right direction. They may not have all the answers. A good doctor doesn't know everything.

Sheila Clemons:

You just take little steps, you know, but you have to live life. You cannot give up. You cannot wallow in your disease. You cannot give up. You have to go on and enjoy life, embrace your family and your friends and help them understand what you're going through. Don't shut off from them because they don't understand it because they don't have it themselves, and you just have to educate them and be patient with them too, because they are trying to help you, but they don't know how to help because they don't understand it.

Dr. Johnson:

The people we spoke with also had some advice for clinicians to keep in mind when managing IPF patients. Let's listen first to Cindy Van't Hof, a respiratory therapist, followed by clinical coordinator Carol Bair.

Cindy Van't Hof:

Don't ignore the patient's symptoms and complaints. I think that's the biggest thing. Pulmonary fibrosis I think is underdiagnosed or not diagnosed until it's advanced. Pay attention. Don't just rule it out just because it's not something you know about. Don't be afraid to say, "Let me look into that," and then do that and let the patient or their family know so that they can learn. And it's not any one... It's not a reflection upon you as a practitioner that maybe you are not the most up on or have the most information about this. There's new information coming out every day. Don't be afraid to learn.

Carol Bair:

So, my hope would be that the physicians in the community, if you have a patient that you've got persistent cough, nothing is working, get that CAT scan. Reach out to a patient care center, because we now have over 40 in the United States that specialize in this disease, and the hope—and the PFF to access the website and see where a center is close to you and get these patients plugged in, because it is such, it is such a—I don't know the right word—a prolonged disease that it not only affects your lungs but the caregivers and the hopelessness that they feel for not being able to do things for them, but there are things we can do, and we try and stay positive on that note and let patients be aware that there are others out there, although it's a rare disease. So, that's what I would offer.

Dr. Johnson:

Two people living with IPF, Kevin Krambeer and Gary Cunningham, also had some advice for clinicians.

Kevin Krambeer:

If they suspect that a patient has pulmonary fibrosis, some sort of interstitial lung disease, they need to get that patient into a Center of Excellence. They might try first to get them in to see a local pulmonologist, but most local pulmonologists deal with sleep apneas and other things that aren't anywhere near interstitial lung disease, and even then those physicians don't see enough of these patients to really know how to effectively treat them, so you're just delaying inevitably this journey. You need to get to a place that does transplants. You need to get to a Center of Excellence.

Gary Cunningham:

It is, and it's true, because I've met a lot of them now over the years from, like I say, all over the country, and they're all the same—I mean without exception. They just are genuinely concerned about their patients. They put in the extra effort. I mean, why should a pulmonologist that I met from Denver, Colorado correspond with me? I mean, there's no reason for him to, but yet he cares. He does. He cares. He cares about me as a person. He met me, and he cares about me, and he responds to my e-mails. I mean, it's like, wow, that's pretty special.

Dr. Johnson:

Before we wrapped up, attendees discussed how the Pulmonary Fibrosis Foundation and its biennial Summit are great resources for improving care for those living with IPF, as well as their caregivers.

Cindy Van't Hof:

If I have a patient whose family is seeking, because it's a fine line that you have to walk, too, but referral to the Pulmonary Fibrosis Foundation. I can't say enough about how much benefit there is to that—and referring people, "Go there, learn what you can." There's also support. You don't have to be computer literate. If you can get on and just read the comments or ask a question, have somebody else who can help you do that for you, it will help you to learn how to cope and make your daily life easier. Don't be afraid to ask questions of your physician or any other healthcare provider that you see, whether it's a respiratory therapist, it's a nurse or whoever it may be, and use everything that's available to you to improve your quality of life.

Kim Gardner:

[W]e just came from the session that they talked about the gastro issues and the sleep apnea session, and that was very spot-on for us. So, it answers a lot of questions for us.

Fran Vettters:

Oh my goodness, we've learned about genetics. We had an inkling that that was an influence, but we didn't know it was such a great influence, and, of course, that's going to lead our children to get tested and our grandchildren. We've learned about management of care. We've also talked to some researchers about things that are in the pipeline. We've had some great people here in the booths that we've garnered information from.

Sheila Clemons:

Well, I learned about the genetic part of it. My mom had sarcoidosis of the lungs and passed away, and I always worry about my kids getting an interstitial lung disease, so I was worried about trying to find out whether they would get it in the future, and I found out that you could do testing on your children to see if they are going to have markers for it in the future, and that's something I would be interested in doing, you know, and just other treatments that I could use to better my function, lung function, breathing treatment, you know, medicines that can help improve your breathing and everything.

Deanne Todd:

So far it's been really interesting. I was telling one of the other ladies I was speaking with that I was looking at the poster presentations that were going on by the academic students and researchers, and I found a lot of them really interesting in all the different aspects. Some of them were a little over my head from a medical perspective, but a lot of them I could understand what it was they were evaluating and what their conclusions were, and I was very interested in all the different aspects of pulmonary fibrosis that they were looking at, both clinical research as well as oxygen therapy and whether or not somebody should be recommended for transplant. All the different things they were looking at, I found that very interesting.

Gary Cunningham:

They invite the patients. They invite their caregivers. They invite all the doctors, all the healthcare professionals, so there's really a great... Anybody that is touched by this disease is probably here at this conference, and as a result it's a great opportunity to meet people, to learn about the disease, about efforts that are being made to hopefully come up with a cure some day. They talk about current treatments. It's really an A to Z total educational program for everybody.

Dr. Johnson:

I want to thank all of the patients, caregivers, and healthcare providers who stopped by to talk to us at this year's PFF Summit.

This is Dr. Shira Johnson for ReachMD, inviting you to be part of the knowledge.

Announcer:

This has been Conference Coverage on ReachMD. The preceding program was developed in partnership with Global Academy for Medical Education.

For more information on this topic, please visit ReachMD.com/PFFSummit. Thank you for listening.