# PAH: The Patient's Point of View


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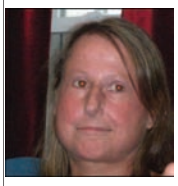

Karin Sears


Kirsten Larson

In a departure from the usual composition of the roundtable—but still within the framework of a conversation among experts—guest editor Hap Farber assembled a panel of clinicians and patients to expand on the information available to providers concerning the real impact of a diagnosis of PAH on patients' lives. On January 11, 2012, after the participants introduced themselves to each other, a frank, and often laughter-filled, discussion on these issues ensued. We trust that you will find the points raised very useful in your role as a PAH provider.

**Dr Farber:** The purpose of this roundtable is to discuss PAH issues from the patients' perspective. To do that, the format of the roundtable today will be somewhat unusual. Two patients will participate in order to provide a unique point of view as to what it means to have PAH and deal with the issues it imposes on a daily basis. For this, I have chosen two health care providers who have long been patient advocates (Robyn Barst and Abby Poms) and two patients who I know to be articulate and very vocal about their disease (Karin Sears and Kirsten Larson). To start the discussion, I will ask the participants to introduce themselves.

**Dr Barst:** I'm Robyn Barst. I was at Columbia University in New York City for more than 30 years and was the Director of the PH Center there until 2008.

**Dr Farber:** Abby?

**Ms Poms:** I'm Abby Poms, manager of the Pulmonary Vascular Disease Center at Duke University. Dr Victor Tapson and I started this program about 20 years ago when conducting the original Flolan trial. My role includes administrative oversight and management of our clinical and research programs as well as direct patient care.

**Ms Sears:** Hi, I'm Karin Sears. I'm 49 years old. I have scleroderma and pulmonary hypertension. I've had scleroderma since 2001. And the pulmonary hypertension cropped up sometime in 2009 and my official diagnosis was made that August. I'm currently on Veletri, with a pump, and I'm breathing better but my whole picture is not very good; I am half-functioning.

**Dr Farber:** All right. We'll get into that and more. And Kirsten?

**Ms Larson:** Hi, I'm Kirsten Larson. I was diagnosed in 1996 with idiopathic pulmonary arterial hypertension. I had no known illnesses before or after. I immediately went on Flolan, under the care of Dr Barst. I then eventually transitioned to subcutaneous Remodulin. And then a few years later, went onto IV Remodulin because of pain issues and social anxiety. I was given at the time the life expectancy of around 10 years. I've exceeded that by 6 now . . . and finished that up by celebrating my 30th birthday with competing in and completing a half-marathon in Orlando, Florida this weekend.

**Dr Farber:** Yep, she did. The plan is to talk about a couple of specific topics and then open the discussion to other comments and questions. The first thing I actually wanted to discuss is—this is for Karin and Kirsten—when you first found out that you had pulmonary hypertension, what did you think? What did this do to you? And at the time, did the physicians or the people taking care of you actually explain this in a way that you could understand and tell you what to expect?

**Ms Larson:** When I was diagnosed at the age of 13, I had been told for most of my life that I was lazy and I was just a regular kid that needed to get up and exercise. And it was meeting with Dr Barst, who finally was able to diagnose me. It was eye-opening, but at the same time terrifying. Because where I'd been told I was normal, I just needed to fix myself and who I was, now I was finally being told I'm not normal, but we're going to try to make you better, even though you're still never going to be normal again. There weren't many people with this, certainly no kids that I could talk to or see with it; nobody in my high school, which I was then going to be attending. But my doctor did explain to me how Flolan was the only thing that was going to keep me alive. But at the age of 13, that was something that was far beyond my grasp.

**Dr Farber:** Karin?

**Ms Sears:** Well, I was older. I don't think I was afraid of it, because I knew there were treatments. And so whether or not I liked them, I had to deal with them. But I knew there was some way to keep me alive. I had faith in Dr Farber, that he would keep me alive.

I think he did explain it to me, because I was avoiding having the right heart catheterization. And he said, "If you don't have it, you're going to die." I said, "Okay." (laughter) I sort of accepted what it was. I think having scleroderma first really turned my life upside down, so this was just another progression of it or just another avenue I had to look into and figure out.

**Dr Farber:** Okay. Robyn and Abby, do either of you wish to ask anything based on these introductions?

**Dr Barst:** I am sure that both Karin and Kirsten were told by their physicians that their treatment was not just to live longer, but would also allow them to feel better.

**Ms Sears:** That he did. Yes, he did.

**Ms Larson:** Yes, absolutely. That is something that I do remember hearing directly from Dr Barst was, "You will feel better."

**Ms Poms:** I have a question for Karin and Kirsten. When you received the diagnosis of pulmonary hypertension, did you feel you had to redefine who you were and what you did on a daily basis, such as working, attending school, home, and social lives?

**Ms Sears:** No, again, my scleroderma is what seemed different; that turned my life upside down. I used to teach and I had to stop a long time ago. So I really don't think my life changed as far as that drastically. With PH my physical activities were harder and harder to do.

**Ms Poms:** And what were those activities?

**Ms Sears:** Well, before PH I managed to go to places like an amusement park with my kids. Or spend an afternoon at the beach. And even things like walking from the car to the beach are getting difficult. Different things—like I certainly cannot get up and run a marathon or go skiing with them—changed a long time ago because of flexibility issues. But I was still managing to do some things.

**Ms Poms:** And Kirsten, how about you?

**Ms Larson:** When I was diagnosed at 13, I was just going into high school. And I immediately chose not to speak with anybody very often from my younger life, and started fresh in high school. I immediately decided to take that summer, learn about my disease, and learn that I was going to be different; I wanted to share that with people and just not hide it. So I was pretty much off and running once I got to high school. I let those around me know and wanted to let people know the things that I was not able to do. I was always told to participate in gym before being diagnosed and would feel so sick after trying and trying to be like everyone else. Now, I had the reason, my doctor told me and my teachers said, "You don't have to participate in these things." But I did make a conscious effort, since I wasn't going to be participating in gym and making social friends in those kinds of activities, I was only going to be seeing them in classrooms, and not in the fun part of gym or of actual playing. I made up for that in chat—talking with people extra and letting them know during my extra lunch hour that I was given in order to study and taking that extra time to talk to people about my disease.

**Dr Barst:** I'm sure that was difficult to tell classmates.

**Ms Larson:** Right. Well, actually how it originally started, I had gone to a public school for about 3 days, a public school with thousands of kids. And I realized I needed more personal attention. I needed to be in a school where people—including teachers—were going to know my name, because I needed to talk with them. So I immediately left that setting, where I would be easily singled out in a more ruthless atmosphere of a public school and went to a private school, where I never allowed the "popular girls" or the older boys to really make fun of me. I really just tried to let people know who I am. I'm a young, pretty girl, and I can go out and I can have fun and socialize with everybody. My close knit friends that I did make all cared. But there was a lot of fear among those that didn't quite understand. They had fear of the central line that I had in my chest that could really be pulled out. That was gross to a lot of people. And it was gross to me. And that would be something that was always hard for me to explain to people, that I do have a permanent line, an open hole in my body, where medication is going through and you do have to be careful of that.

**"And at the time, did the physicians or the people taking care of you actually explain this in a way that you could understand and tell you what to expect?"**

Dr Farber

**Dr Farber:** Okay. We've spent a lot of time here talking about how this affected Karin and Kirsten directly. But obviously they're in somewhat different situations because Kirsten was 13 when she was diagnosed and just starting high school. And Karin was married with kids. The obvious next question is, how did this diagnosis affect the people around you, the people that loved you and, of course, your family?

**Ms Larson:** I know that for my parents, I was an only child, so my mother made sure to be there to pick me up and drop me off at school every day. My parents made sure to be the parents that were always the ones driving everybody everywhere. Making sure I always had my medicine. They were very hands-on. My extended family all wanted to touch me with kid gloves. But there's some that chose to be closer and some that chose never really to take much of an interest at all. And that's still the way it is today. But

those that were closer, stayed close, and are always asking about me. Whenever I'm sick or in the hospital, they make sure to try to contact me or come and see me.

**Dr Barst:** Kirsten, two questions. One: did kids at school, because you're a pretty young lady and individuals who generally are diagnosed with PAH often look fine from the outside, did other kids sort of look at you like, "You don't look sick. What's really wrong with you?" Or, "if you said you can't go to gym" other kids would say "but you look totally fine." Were kids ever like that to you?

**"I had been told for most of my life that I was lazy and I was just a regular kid that needed to get up and exercise."**

Ms Larson

**Ms Larson:** Absolutely. Kids, especially when it came to drinking and we got to those days in late high school, when people couldn't understand, why can't you drink? Why can't you be fun? And you look perfectly fine. Or, why can't you be out late? Why do your parents always have to be the ones picking us up? And why do they always care? It's extremely frustrating to say, "Well, I have to go home and change my medicine now." You're the one that's holding everyone back sometimes. So I was losing friends because I wasn't cool enough to be able to go on certain trips. All my friends went to Italy at one point in high school on a school trip. You do so many of the daily things with people. But then one thing happens and you can't attend. And then once summer comes and the smaller clothes come into play, you feel very alone. Because now everyone is able to see that you are different with your pump exposed. You may be sick but now you have this pump, so you're kind of a freak. You're alone and you're not like everyone else.

**Ms Sears:** I don't think it affected my older daughter. She is 21; she's a senior in college. So she was away at college for most of this. She was used to me having limitations before, so I don't think it really affected her very much. My younger daughter I think was affected more because at this point my husband works nights and he's never really home for dinner, so it was up to me to get dinner ready. And a lot of times, I didn't have the energy to stand there or I'd get out of breath just trying to get things out of the refrigerator. And so I think she felt a lot of pressure to fend for herself, kind of. Or getting tired of helping me with things because she would be the one who would be here most of the time, if I needed something. With my husband, I think it's more pressure because he worries about me. He does everything, though, in the house, so it added to his responsibilities, in addition to working. And when he was home cooking meals, he'd have to pick up the slack on most of the other things. I've gotten to the point where I can vacuum, but I have to have somebody get it out for me and I have to have somebody plug it in, because I can't reach down to plug it in; but I can do some things. It hit my mother pretty hard, I think. She was a nurse. But she dug right in. She's my partner for mixing medicine and she worries, you know, "What if I can't come here to help you do this?" I said, "I'll do it." Or, you know, I'll have somebody else help me. So I think her way of coping is trying to help me as much as she can.

**Ms Poms:** Just to follow that up, Karin, did you ever feel like you were a burden to your family? That you weren't able to contribute in the ways that you wanted to?

**Ms Sears:** Oh, yeah.

**Ms Poms:** Can you talk about that a little bit?

**Ms Sears:** Yes, because I'm not working, so I'm not adding to the financial security. If my younger daughter wants to go somewhere or do something, it depends how I'm feeling, whether or not I can take her. Again, I can't do any of the housework stuff. So, yeah, sure. And I worry a lot, like if something were to happen to my husband, who's going to take care of me, because he does so much.

**Ms Poms:** And have either of you become involved in any support groups for scleroderma or pulmonary hypertension? Can you talk a little bit about your experiences and how, if at all, it helped you deal with this illness?

**Ms Sears:** Sure. I do both. I've only been to the pulmonary hypertension one a few times because I really just found it. I heard about it at the scleroderma group. I was very concerned about a permanent IV and being attached to the pump. It was helpful to see other people with the pump before I got it. And to see that they were living and doing things. And, you know, they didn't look like freaks, even though they have this stupid thing (laughter). There's always somebody there who is suffering more or has more issues. That makes me complain less. And then there are people who do really well, so you get to see that, yes, it's possible to do this. And yes, it's possible to do this.

**Ms Poms:** That gives you hope?

**Ms Sears:** Yes, yes. And I've probably seen attending the scleroderma support group about 6 years now. And I love that group. So we—the scleroderma people—are so different. And there's actually a

person who mirrors me, kind of. We have a lot of the same issues and she's doing so well. And it's good to help somebody with something. You know, if you're listening to them and you've been through it before and you have an answer, or at least an alternative way of doing things, it's good to contribute that way. So I think, yes, they both help me.

**Ms Poms:** And Kirsten, have you been involved?

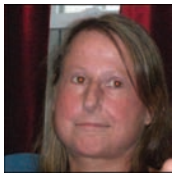
**Ms Larson:** Yes. I was not involved actively with the support group until about 3 years ago, when I decided to start one and I started to see a growing number in the area that I was from. I decided to start a local chapter where I'm from. And we've had our ups and downs with memberships, but we seem to have gained a core group right now. They don't want to be involved with the social media aspect, looking online, learning, and talking on the phone with other patients; they want to see a face. So it helps me, knowing that I'm bringing these people together that need to talk. So having a group is certainly helpful, though I may not get a lot of information about pulmonary hypertension, I get support from all the people, knowing how much they appreciate the group and the opportunity to talk about PH.

**Dr Barst:** Can I ask 2 more questions? You talked about "ups" and "downs." When you were "down," who did you speak with other than a PHA support group or your parents when you were diagnosed? And subsequently, knowing that you're on treatment but you still have the PAH and that the treatment was controlling the PAH and making you feel better, but the treatment was not a cure. Who would you speak with then? Your PH nurse or doctor? Or, are there individuals outside your immediate family that you could confide in and that that helped you?

**Ms Larson:** When I was first diagnosed, I did; I had a nurse, who is no longer at the hospital, who spoke with me constantly. And I was able to ask her a lot of questions. And this was very, very helpful when it came to that. Even though that really wasn't even her area, she did truly go above and beyond. But then as I got older, for a few years I was seeing on and off psychiatrists who oddly enough did not help me.

**Ms Sears:** I do see a counselor. And I had actually seen her prior to pulmonary hypertension, for my scleroderma, so I kept seeing her. She helps me immensely. You know, I always threaten her. I say, "If you ever move or something, I'm coming with you." I'll just follow Dr Farber and her across the country, wherever they go. But—and I also have a close friend that I call a lot and, you know, she listens more than has things to say. But, you know, at least listening is a good thing. And inside my family, Paul, my husband, is very, very supportive. If I get upset, he'll hold me and we'll talk about it. And so I have great support.

**Ms Poms:** In recent years we've focused more on the role and the value of exercise and conditioning for pulmonary hypertension patients. We know you can't change the pulmonary hypertension, but you can affect how you feel physically and maybe improve your quality of life. Were either of you referred to a pulmonary rehabilitation program or do you exercise on a regular basis? What has your experience been with exercise?



**"It was helpful to see other people with the pump before I got it."**

Ms Sears

**Ms Sears:** I'm a couch potato. I actually was an aerobics instructor part-time while I taught. I hate to cloud this discussion, because scleroderma first took away a lot of the things that you're talking about. So exercise-wise, it's really hard for me because the scleroderma limits my flexibility, and creates tightness in my muscles. But I was able to walk and do things. And then the pulmonary hypertension took all that away. I've had my Veletri for 6 months now and I haven't yet been able to get back into a routine because I had other issues. I was very anemic and I felt like I couldn't breathe when I was walking. I had muscle aches and joint pain. So I haven't recovered enough to say, okay, I'm going to try doing some regular exercise right now. Just my daily routine is enough right now. Or maybe not enough, I mean, certainly not enough as far as needing exercise, but it's enough—.

**Ms Poms:** It's what you can manage.

**Ms Sears:** —what I can handle, yes. But I would love to do a Zumba class. I just can't wait.

**Ms Poms:** Good. Now, how about you, Kirsten?

**Ms Larson:** It wasn't until 2 years ago that I even dreamed of being able to do any kind of exercise or walk any distance. I certainly could walk as a teenager; walking the mall was extremely common. But the side effects from that hindered me so much. I was on painkillers from a young age because of the side effects from foot pain and things like that I started also, in conjunction with doing a little exercise, doing a little bit of yoga to clear my mind. That helped with my breathing and that helped me further my exercise. And eventually, I asked Dr Farber if he thought I would ever be able to start running. And he said, "Give it a try." I run now; I can't run huge distances,

but I can walk forever, which is the only reason I was able to compete in this half-marathon. But I would never, ever have dreamed of being able to do that. I also had to be in the right state of mind to do it. Exercise, where I had had doubts about myself, about my thoughts about ever being able to live any kind of normal life or have a huge life expectancy always hindered me. Once I started exercising, those things started to chip away and just fall away, that stress. And that's in the most recent years that I've come to that.

**"You should have a local physician who knows you and with whom you have some rapport—that will make it more likely that he or she will come in at 2 am to the emergency room to see you."**

Dr Barst

**Dr Barst:** One more question for each of you. I think many of us in the PH field have learned over the years that when our patients have what may seem to be a trivial, unrelated medical issue, such as a gallbladder attack or a bad upper respiratory tract infection, and they don't live near their PH physician, sometimes they have seen a local physician who really didn't understand PH well. At least speaking for myself, even if it was a trivial condition, we realized that it was safer to have the patients come back to the PH center, even if inconvenient for the patient and his family. Many patients don't live close to their PH physician. What do you do if something happens, even if it seems trivial such as a bad cold?

**Ms Sears:** I don't live very far; it's only 30 miles or so. So I definitely go to my PH center and Dr Farber when I need something. But I think being knowledgeable about what is happening in your body helps, because well, Dr Farber did tell me that any surgeries that I have, I should have at the PH center because they know that I have pulmonary hypertension and so if I have to have anesthesia, they know what to look for and how to deal with it. For example, I was in a doctor's office who said to me, "Well, you have an IV line. Why don't we just put your medicine in there?" And I said, "No." Because they tell you nothing goes in there. And she argued with me. She's like, "Well, you can just use it." I said, "No, you can't." You have to know these things about PH so that if you're not going to be near your specialty center all the time, you should really know what your body can do and can't do and, you know, when to say, "I don't think so." So I didn't get an IV that day.

**Ms Larson:** Over the years, I was always only about an hour away from my doctor. I had many surgery centers near me, emergency rooms for central line breaks, when my lines would break. And every time I would go to the emergency room, it was a new situation; nobody knew what to do with it. Everybody, like you just said, Karin, everybody wants to shut your line off, put saline through it, put it through your hand, and put in new lines, just flush it, use that as your regular IV, shut your machine off. It's frustrating. So over the years, we just became accustomed to driving an hour to the PH center. Now, I see a doctor that is in Massachusetts, which for me is 5-1/2 to 6 hours away. But I stay in constant contact. If I feel a cold coming on, I make sure to contact my doctor. For PH or anything besides your common cold, I drive to my doctor. I feel it is that important to have someone that knows my history in and out with my condition, because that is first and foremost what I'm dealing with and what's affecting me overall. So he has to know everything, what's going on. So even though that's hours and hours away and very difficult, I have to get to him when something isn't right.

**Dr Barst:** In the middle of the night what do you do if you have an emergency and you're far away from your PH physician? If you need to be seen in the middle of the night and get admitted to a local hospital, you should have a local physician who knows you and with whom you have some rapport—that will make it more likely that he or she will come in at 2 am to the emergency room to see you. And he or she can then call Dr Farber to discuss what should be done.

**Ms Poms:** I was just going to clarify that. We emphasize the need for all our patients to have a local pulmonologist or cardiologist to manage their day-to-day care. And Hap, I think you've told me before, you don't have a coordinator or a nurse that works with you, correct?

**Dr Farber:** Well, for stuff like this, for her, I or the fellows field all the calls. Someone is always available.

**Ms Poms:** Your situation is unique. We manage the majority of patient interactions, helping them deal with all kinds of issues.

**Dr Barst:** It really is important—even if Hap has his pager on and he's in Australia, the issue is, Kirsten, and for all patients, we may think that we are the best person to talk to our patient but if you have a high fever and there is a concern of bacteremia, you may need to get to an emergency room; and if there is a local physician who knows you to some degree, that is always in your best interest. Otherwise, you can look fine on the outside but have something potentially serious going on inside and you could be told to sit and wait in the ER, which could be several hours or more—and for some problems, that can have a bad outcome. You want to have an internist who cares about you as a person and knows when you're sick or

when you're not. And if you're sick, he or she will come into the emergency room and admit you at 2:00 in the morning if you have to be admitted. That's what want your internist to do—and to call your PH doctor. Hospital admissions, even if it turns out not to be needed, is far safer than the alternative.

**Ms Poms:** Right.

**Dr Barst:** The local physician is someone who knows you and knows if you're sick or not. And everyone needs that locally.

**Ms Poms:** We stress that over and over with our patients. You've got to have a local physician who somewhat understands your disease. Our patients can go into any emergency room and there's an on-call pulmonologist here at Duke who is available to advise the treating physician and answer questions as back up for the pulmonary hypertension experts. This is so critical.

**Dr Barst:** That could really be life saving. . .

**Ms Poms:** I know one of the major challenges with this disease is financial issues. Do either of you have issues with insurance reimbursements, obtaining health insurance, or getting disability? How about having limited income? How has this affected your lives?

**Ms Sears:** Because I retired as a teacher with a medical issue, I have health insurance for life. I pay the monthly premium but I'm entitled to health insurance. It was a great plan but with the economy changing, it's creeping up a little more. It costs a little more for this and a little more for that. I did apply for Social Security but because I taught for the last part of my working years, I didn't qualify. However, so many people tell me that's just not right so I'm reapplying now.

**Ms Poms:** So you were denied Social Security Disability?

**Ms Sears:** Yes. Not because I wasn't disabled, but because I was covered by a different plan. And so I do get a teaching disability. However, it's only 15 percent of what I was making when I left. So it's a big financial issue with me. My medicines are—well, actually, for example, my monthly check for my teaching disability is half eaten up with my insurance premiums and the other half goes for my visits and my medicines. So it's kind of like a wash, prescriptions and things. So I'm lucky that I have the insurance and that's a very good thing that I'm thankful for. But sure, if I were to get Social Security, I think Medicaid or Medicare, would pitch in and take care of a lot of the other medical expenses, too.

**Ms Poms:** And Kirsten, have you had financial issues?

**Ms Larson:** I've been very fortunate to have a family that's always had very good insurance with a job with the state, where even after retirement, I was able to stay very well insured. It's something that is constantly worrying to me, knowing that one day it will end. And it's a big fear that something is always on—it's something that's always on the back of my mind—because I know the expense of these drugs. And even putting in the monthly order, I know each time I'm ordering something, I'm trying to be mindful and just thinking about what each thing really costs. And I'm very fortunate now, but one day it's not going to be so easy. So though I'm not faced with any financial difficulty with that now, I was approved early for Social Security Disability, it isn't much money. It certainly will help; it helps with certain household bills, but it's difficult. It certainly makes things difficult, knowing that it can never really be more, and that I'm not going to be able to ever feel well enough to have a job where that can cover my medicine, as well. So I can't go out into the field and work hard and make a lot of money, because even if I were to be feeling better, it's my medicine, that's the only thing that keeps me going. It takes a real toll emotionally, knowing that I can never be financially comfortable. Though I haven't reached any true hardships now, it's hard knowing that those days are going to come.

**Dr Farber:** Lastly, I would like to ask Kirsten and Karin to tell us, from a patient's point of view, how we can be better PH providers for you and the rest of the patients. What do we need to do to be better?

**Ms Larson:** Now, where I'm fortunate, I have always been happy with my doctors. And they've always allowed me to talk to them about what medicines I would like to try or if I'm interested in knowing about something that's coming out on the market, they'll talk to me. But I have talked to other patients about how their PH specialists will not discuss any other drug options with them.

**Ms Poms:** I'd like to frame the question a bit differently. You obviously get excellent care. What would you tell other patients to look for in a PH provider? What are your expectations and what do you need from your provider?

**"Most PH centers are staffed with coordinators like myself that the patients can call 24/7."**

Ms Poms

**Ms Larson:** Somebody that does go above and beyond. Someone that is willing to speak with you, not just always doctors, as they have to take care of a lot of patients. But somebody that's willing to give you a little personal attention, at least when you're seeing them, when you're visiting with them, a doctor that even if they're seeing a lot of patients surround themselves with good people. A lot of physicians assistants and nurse practitioners. But having that core group of people, that are well informed, that are willing to talk with you and let you know what's going on is so important.

**Ms Sears:** I think it's important that Dr Farber is always around people who are trying to come up with new plans. And he seems to be very much aware of what scientists are trying to do, what doctors are trying to do, so that as a patient, you don't get stuck in, "Okay, this is your medicine. This is your pump. This is what you're going to do. And that's it." There's always something. So if he thought that I would do better on something, I believe that he would know that from the people around him and that he would share it with me. I did a study with Dr Farber, so I saw him quite frequently. And I think that helps, because he got to know me better. And it certainly made me more comfortable with him because, as he'll tell you, I am always bugging him and joking and trying to pick on him a little. But so I feel like I could call him and he knows, "This is Karin Sears," he knows exactly what my issue is. And so I think you want a doctor who's open to really knowing you as a patient; not just that you have this condition and this is what we do for you.

**Dr Barst:** I don't want to put words in your mouth but, of course, I am now about to put words in your mouth. I think if you—maybe you don't agree with it, but if you do, I think it might be important to discuss one more issue. And that's that if you see a PH physician and you don't relate to him or her well, or you don't think he/she has the support you need, or they're making treatment decisions and you're not a part of the decisions, it's really important for you to realize that you may need to find another physician. Because what you have is exceedingly complicated, you need someone who you can trust and have a good rapport with. Many of us don't have a good rapport with someone when we initially meet, and he/she might be the wrong physician for you. If you agree, it's something important to tell patients, and in particular—new patients—because they're often terrified at their first PH visit. And they go to see a new doctor and it's sort of like, "Well, whatever the doctor says is gospel." But that might not be the case.

**Ms Larson:** I absolutely agree with it. I think that you should be—I think that your doctor should come off to you as somebody that's a person. That isn't somebody that's put on a pedestal that preaches from up high. That dictates to you what you're going to do and what's going to happen. They have to know who you are as a patient, as well as a person. They have to know—I think it's important that they know what your lifestyle is like and what things are important to you. And that will also help inform who you're going to—what kind of medicines, what treatments are going to work for you and things like that. Especially now that there are so many options out there. There are so many different treatments. You need to be able to have someone that you can have a conversation with and see as a person.

**Dr Farber:** In closing, I really want to thank Karin and Kirsten for their insight and honest assessment of their disease. I know we, Robyn, Abby and I, learned a lot from this discussion. I hope that other physicians and health care providers who deal with PAH will take to heart what these patients have said, will seriously consider the message(s), and will use their thoughts and suggestions as an impetus to become better PAH providers. We all know and understand that this is a very trying disease for everyone involved; hopefully this discussion will help improve the environment to some degree.