The Role of Caregivers in Pulmonary Hypertension Care

This spring, Dr Hilary DuBrock, Mayo Clinic, Rochester, and Dr Charles D. Burger, Mayo Clinic, Jacksonville, Florida, gathered to discuss the role of caregivers in pulmonary hypertension care with Michele Freeman, Eric Olayos, Jenna Olitsky, Dr Scott Olitsky, and LaKeshia Orr.

Dr Hilary DuBrock: Welcome, everyone, to our roundtable discussion with caregivers for patients with pulmonary hypertension. Dr Burger and I are serving as guest editors for an issue of *Advances in Pulmonary Hypertension* focused on the societal and multifaceted aspects of pulmonary hypertension beyond diagnosis and treatment: topics such as mental health, diet, and exercise, and caregivers. Caregivers may be spouses, partners, parents, or friends, and they play an important part in the care of PH patients, but yet we often don't talk about them or their role as an integral member of the care team.

We know a lot about how PH affects our patients, but we actually know very little about how the disease affects caregivers. Our roundtable today is a discussion with PH caregivers to gain insight into their experience and to perhaps provide some advice and suggestions for how we as PH clinicians can better support our patients and their caregivers. Dr Charles Burger and I will be facilitating the discussion. I am Hillary DuBrock, a pulmonologist and pulmonary hypertension specialist at Mayo Clinic in Rochester and Director of the Mayo PH Fellowship program.

Dr Burger is a pulmonary hypertension specialist and Professor of Pulmonary and Critical Care Medicine at Mayo Clinic in Florida and also served as the past Editor-in-Chief for *Advances in Pulmonary Hypertension*. We have several patients and caregivers with us today for this discussion. First of all, thank you so much for taking the time to participate in this roundtable discussion.

We really appreciate your time and also are very grateful to you for all that you do to help care for your loved one with pulmonary hypertension. I thought we could just start with brief introductions. So let's go around the virtual room here so each of you could tell us a little bit about yourself and your role as a caregiver. Michele, would you like to start?

Michele Freeman: Oh, okay. Obviously, I'm a caregiver. My husband has had pulmonary arterial hypertension for 10 years. I'm also a support group leader for pulmonary hypertension, and I do the caregiver facilitator call once a month. Like many other caregivers, I work full time, so just add that in.

Eric Olayos: My name is Eric Olayos, and I've been caregiver for Pam, who's my wife and she's been diagnosed with PAH since 2012. I've been a caregiver since day one. This past summer, she was in Mayo Clinic, Jacksonville, for 60 straight days in ICU. She went into kidney failure. We're dealing with that on top of the PH. It's a long—as Dr Burger has probably known us for quite a while—this is a very tough position. It really is.

Dr DuBrock: Yes, it can be really hard when you're managing PAH and also dealing with complications and the impact of PH on other organs as well. It can certainly be very challenging.

Eric: That's my full-time job. I'm retired.

Dr DuBrock: That sounds like a lot.

Eric: It is.

Jenna Olitsky: I'm Jenna Olitsky. I'm the patient. I've had pulmonary arterial hypertension for 5 years. This is my father, Scott Olitsky, who is my caregiver for—I work full time. He's retired, so he helps a lot with all this.

Dr Scott Olitsky: I'm Scott Olitsky, as Jenna mentioned. I'm retired from clinical practice, a pediatric ophthalmologist. I work on a volunteer basis for Cure HHT, which is the international foundation for hereditary hemorrhagic telangiectasia, which runs in our family, which Jenna has. As you all know, a small percentage of patients with HHT developed PAH.

Dr DuBrock: Thank you both for being here.

LaKeshia Orr: Hi, everyone. I am not a caregiver. I'm actually a patient. I was diagnosed with PAH in 2017. It was already advanced. I was already at function class IV, so I'm not quite sure how long I had been living with PAH. Now I'm happy to report I am at function class I, and I'm doing better on all accounts and living life.

It feels like a second chance at life, and I'm just really thriving and really happy to be an inspiration and to share my story wherever possible. I am the Loma Linda University Hospital pulmonary hypertension support group leader and have been for a few years now. Then just last year in June, I had the opportunity to speak at conference in Georgia. I was on a panel about self-care for PH patients.

Dr DuBrock: Thank you for being here. Do you have specific people in your life who help to support you as caregivers?

LaKeshia: It's a community of friends and family members. It's very interesting to me that so many of my friends know my med schedule. They're like, "Hey, it's 9:00. Did you take your meds?" I'm like, "I'm about to. They're right here."

Dr DuBrock: That's great. It takes a village. You all talked a little bit about who

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you care for in terms of your loved one with pulmonary hypertension. Could each of you tell us a little bit about your roles and responsibilities as caregivers? Do your roles relate to medication administration or just navigating the health care system or communicating with health care providers or insurance companies, just a little bit about what you do in your role as a caregiver?

Michele: I guess I could start with what's going on. My husband was like almost every PH patient I know, was misdiagnosed for many years. Then a year after he was diagnosed, he also developed a brain tumor. At first, the doctors weren't going to operate on because they didn't think he was going to live, and they finally did. A lot of dealing with PH in the beginning was really fighting the system, "No, no, he's not just old." Finding the right doctors, it's almost like dating. You're going to go through a few that just don't work for you, and then getting the health care team put together is the next important step.

Actually, he's doing pretty okay now with meds going from being really, really sick in the beginning. Now it's more supporting him—such as I've got a family calendar with all the doctor's appointments. Is everybody where they need to be? He does have a timer for his meds, but even that he doesn't always do them on time. Like the other day he says, "Oh, I couldn't figure out why I felt so bad all day. I didn't take any meds." I get that a lot. Then the other thing is even helping them emotionally. I think a lot of people don't realize that, with caregivers, our life also changes completely.

We have to change everything and be willing to be part of this. That took a little bit of adjustment, too. I think everybody kind of goes, "Why me?" It was just the black cloud overhead kind of thing. Again, the one thing that keeps me going is the hope. We go to conference—and I am sorry I missed your presentation LaKeisha. You would've been a great presentation, but keeping aware of things, learning what's going on, really keeping me abreast of what's going on in the field I think is really helpful.

It does consume your life and completely change it, such as when we traveled in June to Atlanta for conference. It's like taking a baby. Do we have the oxygen condenser? Do you have everything that is necessary? Did you bring your meds? Seriously, he doesn't remember all those things, and you've really got to make sure everything's there. It's a lot of equipment, but we did it. It worked. It was fun. It took a lot of planning.

Dr DuBrock: Thank you. It's a big responsibility and a lot to remember. Travel and things like that are certainly not as easy as they were before, I imagine. Does anyone else want to discuss their role and what responsibilities and experiences they have had as a caregiver?

Eric: Oh, I'll go next. When Pam was first diagnosed, like I said, it was back in 2012. She had been struggling for about 3 years. Doctors like your normal everyday doctor would say, "Oh, maybe it's pneumonia, or maybe it's bronchitis, or maybe it's asthma, or maybe it's all just in your mind." It really wasn't. She was lucky enough to hook up with a pulmonologist in Chicago. He recommended—he did all kind of tests, and he realized that the condition that she was in was way beyond what his expertise could do. He said, "I'm going to send you down to Dr Mardi Gomberg down at the University of Chicago Hospital." That's where she was diagnosed.

Immediately, she basically started Pam on VELETRI—not VELETRI, what was the one before that? Flolan. She was on Flolan for about a year and a half or 2 years until I finally retired and we moved from the Chicago area down to Florida and down—now we were on the West Coast of Florida, and we came over to the Mayo Clinic where we got ahold of Dr Burger. We've been with Dr Burger. Now since he's trying to transition away from Pam, and now we're working with Dr Moss. I will say that, as far as the technology goes, we're 20 minutes away from Mayo, so we rely on a lot of what Mayo has to offer us to keep up with Pam's care.

She goes to kidney dialysis on Tuesdays, Thursdays, Saturdays, which really restricts us as far as really going anywhere or doing anything. We had gone on about 35 cruises in about the last maybe 15 to 20 years. We've had to forego that now because you can't get dialysis on a cruise ship—you can, but it's very, very, very expensive, and Medicare, and what I have is Tricare, they don't cover it. Everything that we do now is literally for Pam. I used to ride my Harley 7 days a week. I haven't started it up in 3 months. I used to go bowling and play softball. That's out of the question now because I can't really take Pam with us because she can't sit out in the hot sun very long.

We've really had to restrict as far as stuff that I do. I cook. I clean. I vacuum. I do the laundry. I cut the grass. I plant the flowers. I literally make the bed. I literally, literally do everything because she also has extreme osteoarthritis of the right hip, so she can't walk. She can barely stand. She's basically wheelchair bound all the time. It's been extremely difficult and tiring from the time I get up in the morning until the time I lay her in bed. It's literally working to keep her going and keep everything functioning in the house.

Dr DuBrock: That sounds like a lot.

Dr Charles Burger: Eric has always accompanied his wife to the appointments. I have personally and I know my staff have valued that immeasurably. I just want to give props to you guys who have jumped into this caregiver role. We couldn't do what we do without you. Really admire your dedication to the folks that are in your lives that have pulmonary hypertension and to you, LaKishia, who has pulmonary hypertension and your dedication to taking good care of yourself.

Eric: I want to add one more thing. One lucky thing in my favor is that I'm a retired Navy hospital corpsman, and I also have degrees as a medical technologist running hospital labs. That's luckily in my favor. That's the only other thing I'll put into it.

Dr Olitsky: I guess I can go next. Jenna's story is probably in some ways similar about diagnosis. Fortunately, at the time of her diagnosis, we were already plugged into a HHT Center of Excellence institution that happened to be run—the director was also a PH specialist. We were fortunate that, once diagnosis was made, treatment started pretty quickly. That was 5 years ago. In terms of my role, I think, somewhat similar to what has already been said, I manage a lot of special medicine specialty pharmacy issues, getting the meds shipped, watching out for the prior authorizations when they're due, making sure everything comes in on time.

Jenna doesn't need any help dealing with her medicines, but I take on a lot of that role because I do have some of that time, and Jenna works full time. Along the line of what Eric was saying, I don't know how other people can do this. Sometimes I feel fortunate, maybe a little atypical as a caregiver, being a physician, that I know this system a little bit, although it's shocking to me how difficult it can be. Many times, Jenna or my wife has heard me hang up the phone and say, "I do not know how somebody without a medical background could take care of their loved one."

Getting told that Remodulin is not coming on time or that it was denied when insurance changes and just knowing that that's not going to happen, but all the work that it takes, I'm sure as with the rest of you I've been on the phone with insurance companies for hours and hours a day, and I don't know how somebody else who's working full time could do that. My wife, Jenna's mother, also helps quite a bit with some of the things, some of the chores that [are] probably not in her best interest to be doing when we can. Like someone said, I do a lot of research in what's up and coming. I go with Jenna to her appointments to talk to her doctors about options with her care.

Again, I think that's something that I find very important to do. Sometimes Jenna gets a little frustrated with those conversations perhaps at times. Again, I don't know how other caregivers can do that sometimes. I feel very fortunate that I have the time and the knowledge to be able to do that for her. Before the pandemic, I know Jenna traveled internationally a lot. Hopefully, we'll get back to that. I look up and see where centers are to give her the information when she's traveling overseas. It takes a lot of time, as you all know. I know I'm preaching to the choir here.

Michele: I want to jump in on that, too, because I'm a licensed counselor, and I work with people with other chronic illnesses. I know the system, and I found that, sometimes, it's like beating your head against the wall. I thought about that, too: what do people do when they don't know it? At least I'm familiar with what's going on. It is difficult, and you've got to really be aggressive. I used to be nice and nonconfrontational, and now I don't care anymore. You learn to be pushy. You learned to go, "No, this isn't right," and you do what you have to do it to keep your loved one alive.

Dr Olitsky: The squeaky wheel gets the grease sometimes, and it's not the person's fault on the other end. Many of them don't understand what these medications are, that certain medications can never be stopped. Some of it's educating the people at the specialty pharmacies.

Dr DuBrock: Thank you. It sounds like being a caregiver and navigating the health care system is really challenging both before and after diagnosis. After diagnosis, roles relate to disease management and dealing with insurance companies and medications, but also before diagnosis, you as caregivers play an important role as patient advocates to help find the right specialists and determine the diagnosis. That's something I think I hadn't really appreciated is that the role of a caregiver really starts even before pulmonary hypertension is diagnosed.

Michele: The other thing they didn't bring up as many of us travel, it's 3.5 hours one way to the specialists in Portland because, here, there's no local specialist or ones that I would go to or recommend because I know all of them. Many of us will need to travel distances to get the help we need.

Eric: As a matter of fact, we actually moved to Jacksonville from the West Coast of Florida in November just so that we could be only 20 minutes away from Mayo because, otherwise, was a 3.5-hour drive. I understand exactly what you're saying, Michele. I know exactly.

Dr Burger: I have a follow up to some of the things that you guys have said. What have you found to be the value of networking, if at all?

Michele: Without a question, that's why the support groups are so great because people will support and help one another. We tell other members, "Oh, this is what I do," or, "I was having trouble with TYVASO side effects. What do you do to mitigate the side effects?" Also, for doctor recommendations, we're a great network. We just had someone new to the area, and everybody goes, "Don't go there; go here." That really does help.

A patient with pulmonary hypertension can't make it just with the caregiver. There's got to be other people involved with it, too, and other ones that you can ask about. How do you talk to the insurance companies? What do you do? What do you push through? There's always somebody that went, "Oh, yes, I had this problem. This is what I did." It's very, very important to be successful.

LaKeshia: I definitely want to chime in here and say that, whether you have a patient or the caregiver, our relationship with pulmonary hypertension can feel very lonely because of the stats. It's random. It's rare. I think the last time I read a stat, it said that, out of every 1 million people, 15 people have pulmonary arterial hypertension. You're just not interacting with people in your normal life if not for these support groups and these small communities. It's very important that we stay tapped in and connected to one another because, sometimes, it's a relief to know that there's someone else you can reach out to who knows what you're dealing with and can just relate. It's very important, and I love to be in and facilitate spaces like this.

Dr Olitsky: I think one of the things that comes up with networking is especially on social media. It can be good and bad. I see a lot of people asking for medical advice which may not always be the best thing. What is helpful is talking to other patients about experiences. How do they handle a side effect? What can you expect when you try a new medicine? That's been very helpful to network with people for those reasons.

Michele: The other thing I found with any kind of chronic illness and pulmonary hypertension, especially in the beginning or even looking at the two of you patients here in this group, you do not have oxygen on. You don't look sick. There's also difficulties with family members and friends not realizing how serious PH is. I've heard that even though you may have your placard so that you can park in handicaps and the observing public is frowning, the nosy people asking you why you're doing this. I think that makes it harder when you're very much aware of the fact that you don't obviously look like there's something wrong with you, and yet there is something very, very wrong.

Jenna: I will say I experience this in a lot of traveling, especially on planes. You preboard and get many questions, why a preboard if you look so young? You don't look obviously like you need it. I will say that I think I can handle it. It's always nice to have someone else who understands as well if you needed them to explain or if I need someone to help carry my bag. That's why they're preboarding with me and have them also understand that.

Eric: We traveled once from O'Hare Airport in Chicago, where we used to live. We had to have—it was like for a week's vacation on Saint Croix. We had to have like one carry-on for just her Flolan, and we had to have another bag for a CPAP machine because the docs were thinking, at that time, she was having that particular problem. There was one other bag I think for some odd reason or another.

We're there with three carry-on bags, and we walked up to the person that was actually checking our tickets to get onto the airplane. She looked at Pam, and we all had medical tags on all three bags. That woman looked at Pam and said, "Do you really need three bags for medicine?" Like we were trying to make them feel—honest to God. There was another person in security that wanted to take her—she had three pumps because we were going out of the country.

The guy wanted to put it through the x-ray machine, and we said, "No, can't do that." He looked at her, and he grabbed the two extra pumps, and he literally was about a foot and a half away from putting it in the machine. I almost had to grab him by the shoulder, which I'm sure if I would have done that, then they would have had 30 different guys with guns pointing at my head. It's incredible how they don't believe that you're sick. I agree with you, Michelle. It's very difficult. It really is.

LaKeshia: I just wish there was more education, especially in the people who work in the airports, the TSA, around this disease process or what the medicine may look like. When I first was cleared to fly, I went away for a month, and I had all of my little VELETRI cartridges packed in my carry-on bag. I went through security, and they had to swab each one of them individually. All these things, and just like I'm just reminding myself to stay in gratitude because I'm happy that I'm waiting to fly. I'm happy that I'm breathing. Like just be patient. They don't know. This is an opportunity to educate. Sometimes I don't feel like educating people. Sometimes I just want to get on about my day.

Eric: Yes, for sure.

Jenna: Can I tell you how many times I have to explain my Remodulin pump is not a diabetic pump that can't be disconnected to go through body scanner. Then I have to go through a metal detector instead which then gets you flagged, and then you have to go through the whole system. If they recognize it as a diabetic insulin pump, why can't they just recognize it as a different medical device? It might look the same, but it has a different function.

Dr DuBrock: We talked about some of the challenges of caregiving. What aspects of being a caregiver do you find most rewarding?

Michele: I think when they start improving. Like I said, my husband was so sick in the beginning, but he has improved with the right combination of medications. The last time he was in a study, they thought that he was on the actual drug. It turned out he was on the placebo. There is improvement, which is nice that you can see, even though we're told in the beginning you keep going downhill till you die. There can be plateaus or even getting a little bit better. We're seeing some differences in prognosis which was way different than 10 years ago. I think that's what Eric said.

It is difficult to imagine improvements in the beginning. Ten years ago, they were saying with treatment that you died in 5 to 7 years and without treatment 2 to 3 years. That was the way it was. It's nice to see that there's people living longer and pretty good lives. That's what I find the joy of it when you see the person you're taking care of is doing better.

Eric: Pam is now pretty much confined to a wheelchair because of her bad hip. One of the really nice things is that people open doors for us, being a little bit curious. The other thing is that, whenever we go to Mayo Clinic for her various different appointments, the docs are always very, very encouraging. They always tell her that it's not that she's going to get better because she's real serious with her PH, but she's doing a good job of maintaining. That's probably one of the things that Dr Burger and Dr Moss have always instilled in Pam is that her numbers look good, and they've not had to increase her VELETRI. Things are maintaining, which is pretty good.

Dr Olitsky: I would say, as we all know, patients with PH have good days and bad days, and the good days make you feel really good for what you can do to bring those along, being able to do things that might not be possible without our help sometimes. Also, as I mentioned, we love to travel internationally as a family. We hope to get back to that, being able to do some trips. That might mean that we go together just because we feel it's safer be able to do that again. Those are what make the time that you put in worthwhile.

Dr DuBrock: How prepared did you feel to become a caregiver? It sounds like it's a major part of your daily life now, and how prepared did you feel in the beginning to take on this role?

Michele: I don't know. I think I was pretty lost, and that was also before I started working with chronic illness. That's when I realized there was a need for it in my work, and I switched it. Yes, you don't know what to expect. You really are in the unknown. Because like they said, don't go online. Of course, we did, and we all do it. You don't know what to expect. There's good information and misinformation out there. It was hard. I think joining Pulmonary Hypertension Association made a huge difference because then I had a source and found other places and other drug companies that had some really good information. In the beginning, you don't even know what it is. I never heard of it.

Eric: When Pam was first diagnosed, again, luckily, I was a hospital corpsman for 20 years. I had a good background as far as what medical care I'd be able to do for her. Now as she's gotten because of her hip, I've taken over literally a lot more than I started out with. Being a corpsman and, again, a medical technology degree, I was able to do things with her Flolan and her VELETRI. I make her meds every night. That didn't scare me in the least because, luckily, I had that background.

There I've been to some conferences where I talk with some of the guys that care for their ill wives, and these guys they throw their hands up, and they say, "I have no clue what I'm doing." It's just rote memory at this point. I wonder, if I didn't have that medical background, would I have been able to do things like that? Some woman said that, when her husband—after 2 years, he divorced her. Pam was the one that was talking to this woman.

She asked the husband the reason why he's asking for a divorce. He says, "When you first was diagnosed, they said that you may have had 2 years to live. It's been 2 years. I'm out here." We're sitting here going, "Oh, my God, this is the kind of stuff that we hear every day." Being a caregiver didn't faze me, but what has shocked me is the overwhelming amount of work literally that I do from the time I wake up in the morning. Just before I got on this conference call, I had to fold a load of laundry. It just never ends. It just goes and goes and goes.

Dr Olitsky: I don't know how things are now, but when I was in medical school, pulmonary hypertension was probably a paragraph in a pathology textbook. We do have another family member with HHT and pulmonary hypertension. We had some idea when Jenna was diagnosed what this would entail. Better or worse, I was a couple of months away from my retirement. As we all said, I don't know that this would be possible if I was still working to be able to do this as needed when the time comes.

Michele: I'll add to that. Luckily, our son had to get a place to live in and moved back home just temporarily just before my husband got sick. That's the only reason why I've been able to work. I told him, now he can't leave. He's in his 30s. Because it's nice when we have to go, "Oh, got to go to the hospital. Bye. Take care of the dogs." It's like what you were talking about. It's not just me. It's not just me. Otherwise, it'd be really hard. I wouldn't be able to work. I'm able to work because there's other family members here.

LaKeshia: When I was diagnosed, I was actually living on my own, and my pulmonologist, right away, he knew it was going to get worse before it got better. He said that I should not be living alone, and so I moved back in with my parents. Again, the onset of all of this was sudden, but then it was also very severe. Within getting diagnosed, I got discharged from the hospital on oxygen.

We had to make sure there was an oxygen concentrator at my house before I could leave. I got done [with] the pump like a month and a half later. I want to give kudos to CVS Specialty Pharmacy and the resources that they provide because I had a nurse come visit me in the hospital and teach us how to mix the VELETRI and the home visits. I think they were weekly for me at first.

They were very, very helpful to helping me and my family of caregivers adjust and adapt, and having someone that we could call or text or really reach out to with questions was a huge help. The reality of it was, again, it was very sudden. My parents were still working, and they were helping out when they could. My dad was mixing my medicine, but they got tired. I don't know if it was just because of life or because of all of their responsibility.

I actually had to become a little bit more independent, and then I started mixing my medicine myself. It sucks, I have to say it, but it's a reality. Sometimes it can get tiring, and I only felt comfortable saying that after you shared that the husband said he was out after 2 years because I remember someone coming into my hospital—I mean, room, at bedside and saying, "Hey, you have something called pulmonary arterial hypertension." I was like, "Okay."

Eric: A lot of people think that it's high blood pressure.

Michele: Exactly.

LaKeshia: As they walked out, and then I pull my cell phone and I said, "What is pulmonary arterial hypertension?" I pulled up an article that said 27 to 44% of people made it 5 years, and I'm still here, and I'm doing better. I think that's something to celebrate, and I'm very happy to be here and to be able to share. Yes, it was tough, and it was a big adjustment for all parties involved.

Dr Burger: You're to be congratulated on your success story. It's very admirable.

LaKeshia: Yes. Thank you, doctor.

Dr DuBrock: Are there other educational resources or supports for patients or caregivers that you think would be helpful at the time of diagnosis? You mentioned PH support groups and networking have been helpful. Are there other resources that were helpful or you think could have been helpful at the time?

LaKeshia: I think everything that they're doing over at PHA is phenomenal. I wish I would've been introduced to [the] wealth of knowledge and help and personnel there sooner. I don't think I found out about PHA until much later.

Michele: I think one thing that's a little different, but everybody's hinted upon it, it would've been a lot nicer if the doctors here even understood what it was. Even after my husband was diagnosed, he had to go to the ER, they still were still saying, "Oh, it's cardiovascular. You need nuclear medicine imaging." I'm saying, "No, it's not. You are missing something." They ignored at the ER the diagnosis or did not understanding what it is the PH diagnosis. I found that to be a problem. The other misconception with medical professionals is that pulmonary hypertension is high blood pressure.

My husband didn't have high blood pressure at all when he was diagnosed. He didn't have swelling legs, which made it really hard, too, to get the diagnosis. It would've been nice if the medical world was a little more open to it or listen to the symptoms that were given, but because I do not have a medical degree, they discounted what I was telling them. I'm already lost. I don't know what it is, and then when you come across medical people that have no idea what it is either, that made it very hard.

Eric: Luckily, Pam and I were always near centers that had those people that were experts in that field. We relied on those folks from the beginning, University of Chicago Hospital and also Mayo Clinic. We've been very fortunate, and I will be the first person to admit that we rely on—Dr Burger knows Tanya, and she does a lot of work for Pam as far as making sure that the different companies are up to date with the insurance forms and Medicare numbers and on and on and on, although I probably, and Pam does, too—we probably could have done it on our own, but it would've been much, much, much harder. We relied on the Mayo Clinic and University of Chicago Hospital folks, their expertise, in order to get all that stuff done. So, Doc, thank you.

Dr Olitsky: I think we consider ourselves very fortunate to be plugged into some of the people that we've had contacts with actually long before Jenna's diagnosis. I think that's a little unusual that we have those connections, but I would say that, where certain drugs, certainly subcutaneous Remodulin and some of the challenges, having somebody that you can speak to about when that gets started, there's so many challenges, I'm sure, with many of these medicines.

The subcutaneous route of providing Remodulin has some unique challenges to it, I'm sure. We had clinical care coordinators who helped with that, but I'm not sure everybody has that. Probably having somebody to speak to a mentor or somebody that can help you in the beginning would probably be very helpful for many people. I know people have reached out to Jenna when they get started, so I know she's helped some people, and probably there are a lot of people who could use that help in the beginning.

Jenna: I was going to say the peer-to-peer, like LaKeshia was talking about, someone who knows exactly what you're going through. I know I've talked to people on Sub-Q Remodulin before who say, "This location I put it in, it's not really working. What have you used that has worked for you?" It's not something that a clinician can tell you because you're the one who are is doing it, not even the caretaker either. It's you trialed-and-error this that has worked for you, and you can pass that on, and hopefully, they pass it on.

Dr Olitsky: Something as simple as a position, I can tell you, I wouldn't have thought about this. Something as simple as what's the best adhesive to put on so you can take a shower, so you don't have to pull your site when it gets wet and go through that week again. Something just that simple is really the quality of life, the improvement is enormous.

Jenna: Also, someone to, like you say, commiserate with going through site changes, it's someone else who's directly understanding how you feel. Caretakers see how you are looking or see the difference of how you're feeling. Someone else won't understand not feeling like getting out of bed today, how's your site going, or just having that peer-to-peer relationship of having someone who directly understands.

Michele: On the same word of that, I was just thinking, with my husband, having someone that understands how tiring it is to have to take meds every 4 hours really, really becomes really tiring, and I can understand it. Like you said, it's nice to have someone else go, "Yes, I was there with you." I understand, and this is what I've done for it.

Dr Olitsky: I know, in my previous clinical work, there were certain patients with certain diagnoses. I had patients who I asked, "Would you be willing to speak to a family the next time they're diagnosed?" I think, if that's made available to patients, it can be immensely helpful.

Jenna: I won't speak for LaKeshia, but I know, if anyone were to ask another PAH patient if they wanted to speak to them about their journey or what has worked for them or what they've found, there's little tricks we learned to do throughout the day, like getting ready for a trip or how to tell even your friends what meds you're taking or, if you're with them, how they can also understand, which was difficult in the beginning, too, just having that mentorship between someone else who's not just diagnosing you and you have been through it.

LaKeshia: No, Jenna, you can totally speak for me. Yes, I agree. I am that person now, and I'm very open, and I allow people to connect me to newly diagnosed patients, and I'm always willing to talk. I remember, in the beginning, something as simple as not knowing that I had a choice in my dressing cover, I was just using the same thing that I always use until I saw someone else with a different dressing, and I was like, "Ooh, I want that one." I just—it's a matter of asking and requesting it on the refill call. Those little tips and tricks are so helpful, and that's why it's really important that we connect with one another. I think caregivers with caregivers and patients with patients will all just benefit holistically.

Michele: It does help. The other thing that wasn't brought up that also dawned on me is that the patients and, of course, caregivers would be aware of it. There's a punitive aspect with our world. What'd you do wrong? What did you do to get it? You did something. To me, it doesn't matter if you did something. Let's say you took FenPhen or something like that. It doesn't matter anymore, but there is this that attitude, "Oh, you made your bed; lie in it. You did something wrong." I found, in general, because everybody's so stressed, there's not a lot of support for people that fall into disability with a chronic illness category.

LaKeshia: Especially an invisible one.

Michele: Especially an invisible one, exactly. You're very much aware of that even though you're going, "I'm okay." You also know you're being judged in many, many ways by people.

LaKeshia: Yes. I used to use the little motorized scooter cart things in the stores, and I would just always feel like people think I'm playing on the thing. Like, no, it's really difficult for me to walk around the store. I don't want to have to say that, and you're right, Michele.

Jenna: Even as you talked about with handicap placards, they're not easy to get, and I had to ask how to get it for PAH. I asked around because it didn't really fall into a certain category. My walk test is good enough that it doesn't fall into that specificness, but you do get dirty looks when you pull in there with it. I have to explain it's helpful to me. I don't need to walk across a completely empty parking lot to get to a store when you can just be right there.

Dr Burger: One question that I found intriguing that we haven't talked all that much is, what is—what are the best ways to leverage technology, both from the standpoint of being connected as a community but also in your relationship with your providers, good, bad, and the ugly?

Michele: One of the things that COVID brought was telehealth, which was nice, and hopefully, Medicare doesn't screw that up. I hear rumbles about that. That made it good. Then also, I've heard of some companies trying to develop things, and it's not on the market yet that you could even do blood work or something from your house that goes automatically to them.

More communication with each other, a little bit easier communication, maybe that's what I'm getting at. I think technology is going to be really important with it. One of the things that has helped with people in rural areas and other things that you don't have to necessarily go in to get test results. You can see it online. I found technology is going to really help a lot.

Eric: I have to agree.

Dr Olitsky: I completely agree about telehealth, something in my practice we had fought to get for, and then COVID hit, and now it's okay. I think maybe the next step is for many people who have to travel hours to see a physician, maybe being able to be seen offsite by a physician extender who's on a telehealth call with a provider at the same time.

Michele: Oh, that's a good idea.

Dr Olitsky: There are certain technologies now, being able to listen to somebody's heart, that wasn't available 10 years ago, things that might cut down on some of those trips for some patients.

Eric: I was going to say that, since we're so close to Mayo Clinic, what really fascinates my wife is that, no matter what discipline she goes in for an appointment, every doctor has read her profile. The latest information that she has had from her previous appointment is now [in there], and everybody is so up to date on every single thing that's going on with her. That's just incredible for us. Dr Burger, you know what I'm talking about there.

Michele: I like that many of the medical facilities in Oregon have electronic records that talk to each other. You can actually see several different ones at once—I do think that's a really good thing. I also like the idea of having the ability to read the test results as soon as they are completed. I hated it when, in the past, medical professionals would just say everything is fine, and you don't know what they mean. What is fine in relation to what? What do you mean? We're not stupid. I want to see the results along with past trends. I can actually see what the doctors get. Maybe they don't like it, but I think that helps us to be successful with this disease. The more education you have, the better you can handle this.

Dr Burger: Actually, we do like it. It can be difficult at times when results are released before we have a chance to discuss with you because we understand that that can generate anxiety on your part until you have a chance to have that conversation. I think, all in all, you are better informed, having access to the results of your test results. After all, it's your data. We're supportive of that, although there are some challenges from time to time.

Dr DuBrock: We only have a few minutes left, so let's go around the room and see if anyone has any closing comments that they would like to add or any advice for clinicians and health care professionals about how we can better support PH patients and caregivers.

Eric: As far as my aspect goes, I like this idea of having a roundtable dealing with caregivers. I don't think enough emphasis is given to the caregiver. Obviously, it's the patient that we're all trying to make better. I get that. There's a lot of times when the caregivers really don't have anyone to turn to, and I think that anything that comes up dealing with caregivers is a good idea.

Michelle: Yes. The thing I would add is I wish, here, the pulmonologists here would support our support groups. I'd make up a flier. I send it each month on what's on the meeting topic and speaker will be and I get nothing. In fact, that's why our group is still online because we have two members here left after COVID, so our group reaches out to all of Oregon, but it would be nice to have more locals attend.

Dr Olitsky: I think, as someone who's really worn three hats at times, a patient, a physician, and a caregiver, I can't say enough about the physicians we've interacted with. They treat our family extremely well. They're very tolerant of my involvement, I'll say, some maybe more than others. I think our experience is they understand how important caregivers are in this incredibly complex disease.

Jenna: I was going to say the respect of both the patient and caregiver has been very helpful and very understanding. I can't appreciate it enough because I know, if I didn't relay the information sometimes, I know that that's what he's here also for. If it's just me, it wouldn't be relayed as correctly. The fact that they can interact with both [of] us is very helpful.

LaKeshia: I have been so blessed and lucky to be connected to Dr Paresh Giri since early on in my diagnosis. He's been my only pulmonologist. He recently moved practice, and I'm moving, too, because I'm afraid to have to get a new provider. I'm so afraid of having a relationship with someone who doesn't listen to me or who doesn't take my concern seriously. I hear those stories, and it lets me know how lucky I am to have the relationship that do with my pulmonologist, and I just value it. Yes, that's just the last thing I wanted to say. It's the relationships that we have with the providers are so important.

Jenna: I just moved providers, so I understand. I didn't want to let go.

LaKeshia: I cannot let go.

Jenna: I just did. I'm very comfortable. I'm very happy. I understand it took almost, what, two to three?

Dr Olitsky: Yes, for almost 3 years, we were driving halfway across the country to avoid flight.

Jenna: From California to St. Louis.

Dr Olitsky: It was time, but we're fortunate that, although we were nervous, we know we're in great hands still.

LaKeshia: The referral process has been ridiculous. I had an appointment in March, and they said they were going to give me the referral to go see my provider at the new place. Here I am in April, I was supposed to see him April 17th, but the referral still wasn't processed. I was like, "What is going on?" I'm a patient. I just want to trust in the process and in the system that things will get done. It really got to the point where I was just like, "Can I go and pick it up myself? Would they give it to me in hand?" They're like, "They'll give you a copy of the referral." I went to place one, got the referral in hand, took it to place two, gave it to them. Now it's being processed, but I don't want to have to intervene like that.

Michelle: With technology, that shouldn't happen. I've heard complaints with—from doctors, "Why do I have to go through this rigmarole every time with insurance companies?" Difficulties with things such as trying to find the code that is required or even what is covered, it can and should be much easier.

Dr DuBrock: Any last comments, Dr Burger?

Dr Burger: I would just like to express my appreciation to all of you. I've found this conversation very illustrative, and I would agree 100% we need to have more of these discussions and be able to share information like this, connect patients, connect caregivers, connect the entire community around the common goal obviously of ultimately, hopefully, maybe curing pulmonary hypertension, certainly making people's lives better that deal with this extraordinary challenge. Kudos to Eric because I tracked him down at the last minute to connect through, and he was willing to jump in. Thanks to all of you.

Dr DuBrock: Yes, thank you all so much for participating today. It was really helpful and educational for me to hear about how the caregiver plays a role, not just in caring for their loved one but also navigating the health care system, providing emotional support, and also educating the community about pulmonary hypertension. Thank you for participating today and for all that you do.