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## How Patient Advocacy May Change Rheumatology Treatment & Care

Announcer:

This is ReachMD. Welcome to this medical industry feature titled: “How Patient Advocacy May Change Rheumatology Treatment & Care” sponsored by Lilly. This program is intended for physicians.

Dr. Birnholz:

Coming to you from the American College of Rheumatology’s annual meeting in San Diego, California, this is ReachMD. I’m Dr. Matt Birnholz. Joining me today to talk about how to become an advocate and partner with your state and local patient advocacy chapters is Dr. Mattie Feldman, Clinical Associate Professor of Medicine at Tulane University Medical School and Vice-President of the Coalition of State Rheumatology Organizations, or CSRO. Dr. Feldman is a founding member of the Alliance for Transparent and Affordable Prescriptions, serves as chair for the Alliance for Safe Biologic Medicine, and last, but not least, is founder and past president for the Rheumatology Alliance of Louisiana, and she is all over the national and global map now for advocacy.

Dr. Feldman, great to have you with us.

Dr. Feldman:

It’s my pleasure.

Dr. Birnholz:

To start, the easiest way to get going here would be to simply ask you how do we get involved and pose the question that is sort of the center thesis of this interview, but I want to start a little bit before that and get some antecedents here about what brought you to become the advocacy champion that you are?

Dr. Feldman:

Well, thank you for giving me the moniker of champion. I certainly don’t view it that way. Advocacy, in general, I think you identify a problem and you try to figure out a strategy and some type of action plan to address that problem. Probably in the early 2000s when physicians were starting to infuse more in their offices, Louisiana had a sales and use tax that was affecting physicians and making it very difficult for them to infuse in their office, so I went to the State Legislature and found someone that was interested and understood that aspect—he happened to be a pharmacist—and worked with him. We never actually achieved getting an exemption for that, but it taught me a lot about advocacy, and probably one of the most important things is creating relationships and educating. This was a little easier for me because he was a pharmacist, he understood drug supply, the medical profession. But years later that relationship that I formed in a failed legislative attempt when we were trying to pass biosimilar legislation in Louisiana, I went back and contacted Senator Fred Mills, a pharmacist, and worked with him to get biosimilar legislation passed in Louisiana, and it actually worked out really well. I’d advise anyone that’s interested, particularly on the legislative level, is to create a relationship either with the person in office or one of their staffer and make yourself a resource so they look to you for education on certain topics, and then you can look to them to help educate them on policies that you know affect your patients.

Dr. Birnholz:

Why don’t we move from there to a simpler question, which is defining advocacy, because I think some people might get that mixed up or confused with other terms such as lobbying and etc. Tell us a little bit about that.

Dr. Feldman:

I view advocacy and education almost in the same vein. Advocacy, as I said earlier, I think is you find a problem or an issue, you learn

about it, you create a strategy for an action plan and put that in place, and it could be something very simple and very local. Perhaps your hospital has an issue with certain kinds of credentialing and you want to get others to educate the hospital that this is more important, so it can be something on a really local level all the way to international levels. Lobbying is specifically asking for a vote one way or another on a bill, sending out call to action, vote this way on certain issues, so it's a direct asking of legislation from the legislators to have them vote a certain way. Most of what we do is actually go in and use our sort of unique position as understanding how the medical field works when certain policy and rules come out to let them know, "This is actually going to affect the patient in this way. Now, you think about it and decide how you want to vote knowing this information." We always just like to offer ourselves as a resource. We don't really tell them how to vote. We would hope that if we educate them properly and they vote their conscience, they will vote in the way that we would like to see them vote.

Dr. Birnholz:

I imagine it's not a huge chasm to cross between advocacy work and lobbying work when it becomes decided based on an organization's interest or not to actually try to move towards very specific voting behaviors.

Dr. Feldman:

Well, absolutely. When we see a law or a bill that is going to really hurt our patients, we have to go and say, "Look, we don't want this bill to pass, and these are the reasons why." So yes, sometimes advocacy does sort of bleed into a little bit of lobbying, and a lot of the call to actions that the national and state organizations send out to their members to call your legislator, to vote for or against, that is actually lobbying.

Dr. Birnholz:

Before we get into the "how to's," I do want to make sure that we have covered the "why," and I feel like your experience alone that helped propel you to become a strong advocate within the rheumatology field helps explain that, but I want to give you a chance to be able to address that in case we missed anything in terms of helping convince others in rheumatology or the overall healthcare field why they should get involved in advocacy.

Dr. Feldman:

I think physicians know a lot more when it comes to health policy than they give themselves credit for. So, I think, number one, it's important for physicians to get involved because they are a unique resource. Number two, sometimes there's a personal connection. And as we were talking about, I actually—my youngest daughter was diagnosed with JRA when she was 10. I had been out in practice for 12 years already, and even though it probably wasn't in the front of my mind when I was going for this sales and use tax issue, if you have a personal connection, there's a little bit more drive you've got. You're going to stand up for this issue.

That being said, we all have a personal connection to our patients, and so we are not just fighting to get less tax so we can make more money. We are fighting so we can give our patients access to the best care, and I think rheumatologists are well-known for that. Our group at CSRO, we were actually called in by MedPAC one year, because when they looked at the change in behaviors in physicians when sequestration took place, rheumatologists did not change their behavior based on decreased reimbursement, and they were so, I'd like to think, impressed by that to know that we are going to do the right thing for our patient whether we make less money, whether we have less options, we are going to fight for our patients. So, I think rheumatologists in general make fabulous advocates.

Dr. Birnholz:

Which is words to live by. We also have to remind ourselves, in your case, this all did start with a pain point in practice, a patient who couldn't access something that you felt was vitally important for that person's well-being, and it began a series, a chain of events that has now led to you speaking worldwide. I think a number of our listeners and healthcare professionals, in general, who suffer from a paralysis by analysis, a failure to launch syndrome, where they feel immediately self-doubting that: What is that letter going to do? What is that volunteering to speak before any kind of congresses or others that might have me—that's never going to happen, a sudden sense of pessimism as though one person can't make a big change. How do you address that?

Dr. Feldman:

You know, I hear it over and over again from the legislators. "We don't hear from physicians." You don't understand how important it is to hear from the providers, the doctors that are actually in the trenches taking care of the patients. That means more to us than 2000 letters from a lobbying firm. I can't say how important it is to make it your own letter, your own phone call. They really listen to those. And 5 physicians calling their office or sending personalized letters is probably worth 100 form letters. It really doesn't take that much time. You know, if you want to utilize the form letter to give you an idea of how to do it, that's fine, but try to empower physicians into understanding that their one voice can make such a huge difference.

Dr. Birnholz:

Dr. Feldman, what you've spoken about feels as though it could apply to any issue from small to large, from very personal from one

person's practice to something that affects everyone, but speaking from your experience now as a founder, a representative, a president of multiple societies in rheumatology, can you just iterate for us some of the most pressing issues that you think need the most amount of advocacy right now?

Dr. Feldman:

I think state-wise the thing that we're working on finishing is getting biosimilar bills, and those are bills that allow physicians to prescribe biosimilars that are now being approved by the FDA, and I think one of the things that we're really trying to get in those bills is physician notification from the pharmacy. Once a biosimilar has been deemed interchangeable, which none of them have been yet, but once they have, there can be automatic substitution, and we would like to know if the substitution takes place. Pharmacovigilance is very important, so we're still working on that. There's still some states that have not passed biosimilar legislation.

Step therapy, nonmedical switching and prior authorizations are all what are known as utilization management tools. We've learned over the years how pharmacy benefit managers essentially hold all the cards when it comes to formulary placement and pricing and drug distribution. So, in learning that essentially those issues of step therapy... If you don't know what step therapy is, it's you have to take this drug followed by this drug before you can take another drug. Nonmedical switching, your patient's stable on a drug; they change plans; the plan changes PBMs; all of a sudden everyone has to move over to another drug, not for any health purposes but strictly usually financial reasons. So, we've learned that these have all sort of trickled back to the pharmacy benefit managers, so we're trying to attack that issue from both ends. We're supporting rheumatology state societies around the country in getting step therapy legislation passed along with nonmedical switching. We're also trying to educate on every level starting with our patients. "Why is it that when I tell you about 9 biologics that have been approved I can only give you this one? It's because that's the only one your insurance company will pay for." So, we start with our patients.

Dr. Birnholz:

Well, Dr. Feldman, I have to say you have perfectly encapsulated the idea of being passionate about your issues. We began our interview with that theme, and we get to end it and round it off in the exact way, and I thank you for that.

Dr. Feldman:

Thank you.

Dr. Birnholz:

I want to thank my guest Dr. Feldman for joining me today to talk about advocacy and partnership work in rheumatology organizations.

Dr. Feldman, great having you with us.

Dr. Feldman:

Thank you so much.

Announcer:

The preceding program was sponsored by Lilly. If you have missed any part of this discussion, visit [ReachMD.com/PatientAdvocacy](https://ReachMD.com/PatientAdvocacy). Thanks for listening. This is ReachMD. Be Part of the Knowledge.

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