

# INSIGHT

## Conversations with Thought Leaders



**American  
Autoimmune**  
Related Diseases Association, Inc.

This is the first in a series of conversations to bring new information and compelling perspectives on issues of critical importance to people with autoimmune diseases and stakeholders. Through interviews hosted by AARDA President & CEO Randall Rutta, *Insight* contributes to our understanding of issues and ideas, best practices, and strategies for change in support of the autoimmune community and society.

Meet Lee-Anna. Her story is unique – she is a patient with an autoimmune disease, a nurse practitioner and an advocate. Lee-Anna was forced to plan her funeral at the age of 36. She battled the harmful effects of step therapy and is a dedicated advocate that travels the country to encourage changes in access restriction policies including harmful step therapy practices. Read more about Lee-Anna's efforts to educate decisionmakers and help others become advocates.



*Rocky (Lee-Anna's husband), Lee-Anna, AARDA President & CEO Randy Rutta*

### RANDY:

**Q.** Lee-Anna, we are excited to have you share your insights on what it means to live with an autoimmune disease, what you've learned from that experience, and what you might want to share with others that have health challenges, their families and friends, legislators, others who really need to better understand how they can navigate their lives and be as healthy and happy as they can possibly be.

### LEE-ANNA:

**A.** I think that's one of the biggest things that people want is to be heard. A lot of times as a patient with a chronic condition, sometimes I think you feel like over time people may not really want to hear about it anymore. In the beginning, when someone is diagnosed with a condition, especially if you have anything that could be a rare condition, people are very interested in knowing what that is, but over time that interest fades away and I think we have to find a way for people to continue to be interested in learning more, helping to

continue that discussion, and finding a way to get research and more education out there for people to find out more about all conditions, not just rare conditions.

### RANDY:

**Q.** How did your health battle begin?

### LEE-ANNA:

**A.** Trying to find a diagnosis was pretty exhausting. It took more than a year to be correctly diagnosed with Behcet's disease. I think that there are probably people

that suffer with conditions for many, many years before they're ever diagnosed. They just slip through the cracks. So I think that we need to pay more attention. How do we educate people to put all those clues together more concisely? That's the real question and why I'm speaking up and engaging.

#### **RANDY:**

**Q.** I know from reading your story that you were horribly impacted by step therapy. What did you experience with barriers to getting access to the right medications?

#### **LEE-ANNA:**

**A.** Lots of the issues that I had can be attributed to me being forced to “fail first” and prior authorizations. If you get a prior authorization for a drug through your insurance company, sometimes either they're too expensive for you to afford, or if you do get approved for it, if the drug doesn't work and you have to switch to a different drug. Many times, the insurance will require you to try multiple drugs or to fail first on multiple drugs.

During this two-year battle with insurance companies, my condition worsened, and I was practically unable to do most things that most normal people could do, and we had to stop the drug.

I was basically in a desperate situation where I had to choose between continuing to suffer and be

sicker and unable to function at all...in hindsight looking back at that, my hands were tied and I was desperate.

#### **RANDY:**

**Q.** How much of your struggle was related to the barriers that prevented you from accessing the medicine that your physician wanted you to have and you felt would work, but was unavailable to you?

#### **LEE-ANNA:**

**A.** Insurance required me to try three drugs and mandated that I had tried drug A, B, and C, so then they could say I failed these three drugs so I could try another drug so insurance would pay for it.

There were other drugs that were available, other drugs that my physician would have deemed to have been better or more appropriate for me. I know over the years, my physician and I have a great relationship, he's been my physician for decades now, and he has said openly that he would prescribe many medications if he knew that insurance would allow it.

But he's familiar with the harmful step therapy drill and therefore he does not even attempt to prescribe those. That should be illegal. If you have a physician that has a medical degree, has the expertise and the knowledge, knows that it's evidence based medicine and practice and he wants to

prescribe a certain drug to his patient and they are agreeable to that drug, then he should be able to write that prescription and they should be able to try that.

The way it is today, physicians are often cut off at their knees. So they have decided to throw their hands up in some ways, not because they're bad physicians, but because they have hit so many roadblocks that they do not have the time in the high pressure demands of medicine today to be able to have the autonomy to do that anymore.

#### **RANDY:**

**Q.** As you're aware, through AARDA and Let My Doctors Decide, our goals are to strengthen the ability of a physician working with their patient to access the most effective medicines, because they are the experts and they know what is going to be best for that patient. Have you had the opportunity to talk to state and federal policymakers? Do they understand the issue and the urgency?

#### **LEE-ANNA:**

**A.** Last year in Tennessee, there was an effort on a bill that was partly geared towards step therapy, and also to allow patients the ability to access off-labeled drugs for certain conditions. Unfortunately, the bill did not make it out of Committee. This year in Tennessee, there is a new bill to step therapy reform, and we are

hopeful that it will pass and become law.

### **RANDY:**

**Q.** Policymakers and regulators need to hear from people like you that are living this experience and understand these barriers, and what they could do to make sure that it's the patient and their physician that have the ability to drive healthcare decisions. It's not a 'one size fits all' scenario. Your experience tells that story. What have you shared with patients and physicians? What have you learned and what would you suggest others do?

### **LEE-ANNA:**

**A.** I think educating patients to let them know that they have the ability to ask is critical. I think that many people may not know that whatever they're being recommended may not be the best or first choice that their physician would want for them.

When I was working as a family nurse practitioner, I had patients that would come in and they would tell me openly that they needed a certain medication. It was what would work best for their condition, but they would also say 'My insurance company won't pay for this unless I take these two medicines first. So I need a prescription for this medication, but I'm not going to take it, or it's not going to work because I've tried it before. I have to do this because my insurance

company requires it.' Now that's insane. There should be no reason why their physician or provider could not prescribe them the medication that would be best and work best for them. To force them to take one medication for 30 days or 90 days and it not work, and take another for 90 days and it not work, you should not make people do that.

### **RANDY:**

**Q.** What can AARDA and LMDD do to advocate on behalf of people with autoimmune disease? Our efforts focus on enhanced research so more medicines are being developed, promoting affordability and access – but what else can we do to help patients?

### **LEE-ANNA:**

**A.** I think one of the best things that we can do is educate people and patients that it is okay to speak up and ask for what they want, because patients have become afraid to say what they want because they're afraid that they will lose their doctor, that they'll lose their insurance, that they'll be seen as a troublemaker, that they will be seen as noncompliant. I say all these things because as nurse practitioner, and also as a patient, I know the other side of the fence. Sometimes, when a medicine doesn't work, I think, 'I really don't want to not give this a chance. I don't want them to think I'm not trying.' I think people want to make their

physicians happy. They want to make their nurses and whoever's taking care of them happy, but they have to do what is right for themselves, too. They need to know that it is okay to ask questions, that it is okay to say, 'I'm not comfortable with this,' and when someone says you need to do this or you can't do this, it is okay to ask why. I don't think we ask why or why not enough.

### **RANDY:**

**Q.** So, we can certainly advocate on behalf of patients, helping to educate and engage patients and the people around them, and do a better job in creating an environment where there's that understanding and that permission for people to advocate for themselves.

### **LEE-ANNA:**

**A.** Yes. Sometimes, patients have a patient advocate, someone that comes in and advocates for them, but we often forget to tell the patient you can advocate for yourself too, and it's okay to stand up for yourself.

### **RANDY:**

**Q.** What about family members, friends and other supporters? What is their role in this process?

### **LEE-ANNA:**

**A.** The role of your family members is significant. I know that my husband doesn't realize how much of a backbone he is for me.

Sometimes you go out and people think, especially with autoimmune diseases, 'Oh, she looks fine,' and they don't know that that person's husband helped dry her hair that day, or they don't know that that husband rubbed somebody's back all night the night before.

In my case, what helped me to continue to work was that my husband drove me to work and picked me up so that I could work a little longer. He takes me to my doctor's appointments and he helps me to remember things when I can't remember them. Sometimes it's okay that you can't remember things all the time, and that's difficult to admit, but your family members love you and they're okay with helping you do those things.

#### **RANDY:**

**Q.** I know that it's not easy for family and friends to see someone they love struggle with the barriers that you encounter, and they're right there with you, side by side, so we certainly appreciate that. I think as organizations that advocate for patients, it's patients and their families, physicians and researchers that are back in the clinical laboratories trying to find that new medicine – it's that entire community around people with the patient at the center, empowered to advocate for their health.

#### **LEE-ANNA:**

**A.** Yes, often times your family or friends can listen with you, ask more questions, and help if you're having difficulty to explain something to your physician, they might be able to explain what you can't. It helps to have that backup because you can explain something differently.

#### **RANDY:**

**Q.** What's the one final thing that you would want to leave the people that we're sharing this story with, one last call to action? We will be with you, we'll be with you in Washington, DC to get the Safe Step Act passed. We'll be with you at the state level to help people understand these barriers like step therapy and utilization management have to be changed. But what's that one last message for people that you would like to leave with them?

#### **LEE-ANNA:**

**A.** I guess I would want people to know that there's always hope for something better, that things can be different and they will be different. It might not feel like today that you'll ever get to a different place, but I believe that with many people trying to rally together to make a change, we can make a great impact. I believe that no one should have to make a decision to do something that they know is harmful to themselves just to try to feel better. I think

that there should be options available to people that are reasonable options, options that are safe.

#### **RANDY:**

**Q.** Well, Lee-Anna, we share that hope with you and we're glad to have you on the front lines helping so many people out there with autoimmune diseases and those who are struggling to get the medicines that they need. You've been a pioneer in your own health to get to where you are today, and we really appreciate you being with us, sharing your story and being an advocate for everyone who is facing similar challenges and who just want what you want – to live a healthy, happy, productive life. We really appreciate it.



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