



## Voices of Value Speak Up Living with Psoriasis

### EVENT TRANSCRIPT

Terry Wilcox: I have a little bit of house keeping to care of here first. My name is Terry Wilcox I'm the Executive Director of Patients Rising, and welcome [this morning 00:00:08]. Before I do anything else I would like to thank [Bob 00:00:11] for that video. He's one of our panelists tonight. He's right over here. He produced that a couple of years ago and was lovely enough to let us play it for you here tonight. We're going to be doing a live poll at the end of this- towards the end.

All you have to do to participate is text from your phone. Before you can do what it says I need you to text patientsrising, all one word, to the number 22333. If you just dial 22333 and then [text 00:00:59] patientsrising no space all one word. Well, of course we're not up there patientsrising. Then that will [inaudible 00:01:08] when we get to the poll you [inaudible 00:01:11] poll and your live answer will come up here on the screen.

Female: What's the number?

Male: The number is-

Terry Wilcox: 22333 is the number and you just text the words patientsrising all together. Then it should text you back. It will say you've joined patientsrising session. Then you can participate in the poll. Thank you all very much for attending. We're going to get started here in just about two minutes.

Male: Did everyone get it? Did everyone get it?

Terry Wilcox: Everyone get it? Okay that's great thank you very much and like I said we'll get started here in just a minute. Give it to him. Okay wait one second. You go get over here and get ready to come on. Wait not yet. No, okay. That's fine, that's fine, that's fine. I was going to wait a couple minutes.

Male: [crosstalk 00:02:28] around 7:30 [inaudible 00:02:29]

Johnathan : Hello, and welcome, and good evening. We are live from the Smith and Wollensky Castle in Boston's back bay. My name is Johnathan Wilcox I am the Policy Director and the co-founder of Patients Rising. We're honored you honor us by being here tonight. I want to say a quick word about the video we quickly saw. Who we saw, and I say see [only 00:03:11] [inaudible 00:03:12]. You saw the video, you saw those people, those are patients what was missing? What was missing in that video?

Male: [inaudible 00:03:22]

Johnathan : Pardon me. What was that sorry?

Male: [inaudible 00:03:25]

Johnathan : The voice that's right. I thought what was interesting about it is, some of you say the sound, well it had sound, it had sight, it had made sense. You saw that it didn't have the patient voice, and without the patient voice you see that we had essentially nothing. We had essentially nothing. Our organization was found for that purpose. It was founded to bring volume to that voice, because ultimately as I said without it we have so little. That is because ultimately it is a voice of value. It is a voice of the highest value.

We have come to Boston- anytime is the right time to come to Boston, but we have come to Boston, because a deep concern for patients, for psoriasis patients has come to Boston. An organization called ICER the Institute for Clinical and Economic Review will be at Harvard medical school tomorrow perhaps appropriately. They will take aim at the medications for psoriasis. How will they do this? They will do this through the application of very complicated mathematical formulas called value frameworks. To us their value frameworks are not what we hear patients mean by value.

They are all but certain in taking aim at medications to approve caps on patient investments. Ceiling's on patient medicine, limits on patient treatment, and ultimately then with it all inevitably the barriers to patient access. As you will hear tonight these barriers are real, these barriers are real. We are speaking out not because ICER is bad people, but because they are wrong. They are dead wrong. ICER is concerned first and foremost with the maintenancing of a system, and managing.

We are concerned first and foremost with breaking down those barriers to access, and connecting patients to the medications they need and deserve. Ultimately this is a fight. This is a fight between the narrow focus of the value frameworks that conclude we believe and we fear that see ultimately patients as commoditized drains on resources not as a community of human beings. We know how to diagnose, and treat, and hopefully one day cure.

This makes Boston then the perfect place for the patient voice of value to continue what is we needed for many years, which is a psoriasis conversation. We ask you tonight then to listen to a voice. It is a special voice. It is a specific voice. It is often a quiet voice. It's often a muted voice. It is the patient voice. It is the patient voice of value. In that fight patients are everyday fighting. They're fighting. They're fighting for their livelihood. Some are fighting for their lives.

That is why we fight. That is why patients rising was formed. Right here today the patient voice of value all night long will speak up. It will speak loud. It will speak clear. It will speak convincing. I am convinced you're going to love what you hear. Thank you very much. At this time it is my high honor and distinct privilege to present to you the director of AMJAM Corporations Director of Advocacy Dina Darlington.

Dina Darlington:

Well thank you for that warm welcome, and thank you for that very kind introduction Johnathan. As Johnathan indicated I am Dina Darlington. I'm the Director of Advocacy at AMJAM, and I am really honored and pleased to be here today. Before I go onto the introduction of a very special patient that we have as a guest this evening. I'd just like to thank Patients Rising for the work that they're doing, and the platform that they've created to really provide a voice for the patient. I think that, that's central to the work that we do at AMJAM. We really try to keep the patient in the center of everything that we do. We thank you for providing this platform to elevate the patient voice.

As I mentioned I'm here to introduce a very special guest. I really don't think that he needs much of an introduction at all. I think that we all know him. I think I'm pretty safe to say that we love him as well. Jerry Mather's has had an extensive show business career that began at the tender age of two when he did a pet condensed milk commercial. He continued to work on many of the early 50's television shows. In 1954 he made his first movie debut with increasing roles to follow throughout the 50's. It was in 1957 that he debut in the series Leave it to Beaver, that Jerry enter the hearts and homes of America. An immediate success the show gained national attention and ran for six seasons totaling 234 episodes.

When it celebrated his 50th anniversary on October 4th, 2007 the show became the longest running scripted show in television history. Currently shown on TV land and in countries through the world Leave it to Beaver has made Jerry and American icon. He has appeared on commercials, television shows, and Broadway. What we may not know about Jerry is that he is a tireless patient advocate, and in the mid 90's Jerry was diagnosed with Type II Diabetes. He took preventative action, lost 55 pounds, and is currently one of the leading lecturers on living with and dealing with diabetes.

Jerry has partnered with diverse organizations to bring awareness of this epidemic that our country is currently facing among both children and adults. Jerry currently participate with [inaudible 00:10:17] The Help is Here Express

which is a national tour bus to help uninsured and financially challenged patients obtain prescription medications for free or close to free. The bus tour is part of the partnerships for prescription assistance and nation wide efforts sponsored by American pharmaceutical research companies raising awareness of patient assistance programs, and the need to effectively address the rising and alarming rates of chronic disease. In addition Jerry suffers from psoriatic arthritis, and is here with us this evening to share his personal journey and experiences with this disease. Without further delay please join me in a warm welcome to Jerry Mathers.

Johnathan : One star on stage I'm afraid of tonight. Everything that Dina said introducing you has come from what you share as a performer and now you take on a different role. The role of patient advocate is one that takes many forms. In some ways you've told us early that the best advocacy has a authenticity to it, and a reality. What do you mean by that?

Jerry Mathers: Well, when I found out that I had psoriasis I looked around for information about it

Female: [inaudible 00:11:54] Jerry's mic's not on. [inaudible 00:12:00]

Johnathan : I'll take that. How about that?

Jerry Mathers: Probably sounds a lot better now.

Female: [inaudible 00:12:07]

Johnathan : I could hear him fine.

Jerry Mathers: When I first found out that I had psoriasis I looked around for information about it and I found that there was very, very little. I had been an advocate for diabetes which, I at the time that I discovered that I had diabetes, was very, very over weight. I was about 35 to 45 pounds heavier than I am right now. I had worked all my life. I had been a working actor since I was two years old.

Johnathan : Before that were you working at before two?

Jerry Mathers: No, I was a slacker.

Johnathan : Just laid around the house?

Jerry Mathers: Slacker, yeah. Didn't even go to the bathroom. Had diapers what can I tell you? In fact the very first show I did was a pet milk commercial that I walked out on stage at two years old in six guns, cowboy boots, a cowboy hat, and diapers. That's how I started. When I started knowing that I had diabetes I was very, very shocked. I had put on a lot of weight, and then the doctor told me- I noticed that I had an outbreak when I was- I finished Leave it to Beaver. I basically in

some ways, since I had been working since I was two, went to a regular high school. I then spent six years in the military. I was in the Air Force and in the International Guard.

All of a sudden I was playing soccer and got kicked in the leg and my leg- The person I was playing with, it was fraternity intramural game, had on a steel toed boot and kicked me in the leg. My leg swelled up. Being I thought a tough fraternity person I just ignored for a few days. Then I went to the UC Berkeley hospital and the doctor looked at it and he said, "Well you've got a very bad" basically not infection but, "your leg is swelled up. It will go down," but he said, "that'll be better, but there's not much I can do for that patch of psoriasis on your bottom." I was very, very shocked. I honestly had no idea. I knew that I had what I thought was a rash.

I was a fraternity guy, and I probably wasn't showering as much as I should have been. I just thought okay this will just go away it's you know ... I said, "Well what can I do about it?" What he told me was, "There's probably not a whole lot you can do," and that really shocked me, because my lady said, "That's going to get better, but the psoriasis you're just going to basically have to learn to live with." I did and I noticed that my psoriasis tended to get worse around finals, and other things that were very, very stressful for me. It was always there, but there wasn't really a whole lot I could do about it, so I went on with my life.

About 15 years later I was on The Tonight Show with Jay Leno. This was about the time the Survivor reality show was on, and we did parody of it. One of the things that the survivors did were eat odd and peculiar things. We did- it was a relay and it was with other child actors. I was the team leader for mine there were five of us. They said one of the things we were going to do is you're going to eat something that's alive. Well there were three girls and me left on the team, so guess who was going to eat something that was alive?

Johnathan : Now that's a team leader right there.

Jerry Mathers: Yeah, right. Not too bright though because on The Tonight Show because it's such a prop heavy show they have about ten prop guys. The director said, "We want something that can be eaten alive." They sent the bottom guy and he brought it back, and the guy gave it to him and it was what's called a grub. It's fed to animals, and snakes and it's big about the size of a slug, and white. They said, "Okay this can be eaten alive."

Johnathan : These people are still eating Jerry. I want you to know that.

Jerry Mathers: I know you asked a question.

Johnathan : I did.

Jerry Mathers: I did swallow it. The person at the pet store had said, "It's going to have to be boiled," but they wanted it moving and they don't move a whole lot when they're boiled. I did swallow it I got a very, very bad infection in my intestines and was in the hospital for about six weeks. At that time my psoriasis really flared up. The psoriasis was almost as bad as the infection, and it didn't go away for almost two years. That's when I really discovered what psoriasis was about. In some ways, if it can be said, that I was lucky. I was lucky it was on my buttocks and my legs, so it wasn't- I know a lot of people get it on their elbows. At the time, or a little shortly after that not shortly but within a few years, I met a woman who I married who had psoriasis.

I have my wife with me here tonight. I've told her that I was going to talk about this, because it's not the same wife. She had a very, very bad case of psoriasis, and because I knew about it I knew it wasn't in anyway contagious, but we had a lot of problems. I have three children with her. One of the children the doctor suggested that we might want to terminate the pregnancy, because when she was born she could possibly be blind, because of the psoriasis. We chose not to do that, and I have a beautiful daughter that's just now given me, within the last year, my first grandchild. I know not only living with psoriasis, but also being a care giver for someone with a very, very bad case of psoriasis.

Johnathan : You persevered through. One thing I speak to tonight is today you publish an opinionated editorial and publication called The Hill which is a leading newspaper of the Washington DC scene. I was really fascinated by what you wrote. It was really did it the right way. It is addressed essentially to policy makers, and politicians, and regulators, at all the levels. What you said was less- it wasn't a political opinion. It was really about what you said was to put the patient interest first. In a lot of ways what you described was there are so many ways for us to deal with healthcare challenges with access issues with all the other issues. What you said specifically was that, "To place something first and let it be the thing that we drive through the most."

Jerry Mathers: Well, I think that's very, very important that people a lot of times there's in any business arrangement there's always a person, and then there's the money. A lot of times the money becomes more important than the person. Especially with diseases like psoriasis, but a lot of diseases. You can't really make that judgment, because in my opinion people are always more important. When it becomes a choice between the two I always pick the person. That is probably my goal is to help people and not really care about what it costs. I feel that every life is important. The quality of life is not as important as the life itself, but it is a very, very important part of the equation.

Johnathan : Here's a man who says it all. The great Jerry Mathers. Thank you very much.

Jerry Mathers: Thank you.

Diane Talbert: The first 48 [years of 00:21:07] my life I was [inaudible 00:21:09] and covered in psoriasis. Then spent 40 years [learning to bear with my life 00:21:12]. Back then I [inaudible 00:21:18] about ten years ago he said, "Let's try these treatments [inaudible 00:21:23]" That's unheard of [inaudible 00:21:26] people to help you we have [inaudible 00:21:29] putting me on a level deeper than I had been before. Which made me sick. It made me tired. It made it where I really couldn't get out of bed. It took six months with me and my doctor fighting the insurance company to get an approval through my insurance to get the drugs. If you could picture it I had scales all over just little- I had it all over. I got the greatest husband ever. When I met my husband I was [inaudible 00:22:05] covered in scales. [inaudible 00:22:08] who loves me for me. Who didn't see the outside who saw the inside that value. My whole life has been painful but, [I love it right now 00:22:19] even with psoriasis [inaudible 00:22:22] I wouldn't change anything, because I'm just happy to give back.

Johnathan : That's an amazing voice. Now meet her here live Diane Talbert.

Diane Talbert: [inaudible 00:22:46]

Johnathan : I love a woman who brings her own sound. That's an incredible story. That was remarkably unedited. The thing that overwhelmed me about your story is how long this has been a part of your life. Yet as I meet you, you have such a [distant 00:23:12] experience. You give lift to the patient voice in ways that I have not heard, and as we come to learn about psoriasis. What is it that you most take with you when you speak about this issue?

Diane Talbert: My experience. I've had this disease for over 50 years. I've the psoriatic arthritis for 25 of those years. I went through hades and back with this disease. Just being able to come to things like this being here is this amazing journey for me that where I was, where I've been, and where I'm going to that helps me.

Johnathan : I want to tell everybody that videos one take. I want to let you know. This is one take Diane and what I mean by that is you just tell, and your share, and you come through. I think you've thought about for as long as you've been dealing with this. To me is look how you've come through. You're also an innovation victory, you're also an advanced victory, and an access victory. You're able to get things that let you live your life. You're in control of your life. 50 years I say another 50 you're in control now. Look at you, so to me this is- your voice speaks to that even when you don't use the words.

Diane Talbert: I like giving back, I like helping people, I like sharing, I like- I share my story to help others. I don't share it for pity. I share it so other people can see that you're not alone in this journey. You can come out fighting on the other side. I just can't explain it. It's just been a journey. It's been from the time I was five years old going to school. They wouldn't let me in school, because I had psoriasis. I was covered from head to toe. They thought I was contagious. They took me to a hospital and quarantined me at five. Even going through that, and

then even as a teenager and people staring and pointing and going, "What is that on you?" Trying to overcome that.

Even as you get older going to the hair dresser and the lady going, "When is the last time you washed your hair?" "Why are you so dirty?" It's been a really, really hard struggle. Not being able to go to the beach, or the one time I did go to the beach I wore four pairs of pantyhose, because my psoriasis was so bad. It's just a journey. You've got to be there. I've been where the scales were just falling off me, or I've had to wear long sleeve shirts, put rubber bands around them so the psoriasis wouldn't fall out. I have had people, if I go to shake their hand, they'll back away from me. I was asked to get out of the pool-

Johnathan : I'm going to hold this hand.

Diane Talbert: I was even asked one time- I went to a pool it was just a public pool. The guy came up to me and goes, "You can't swim in the pool." I goes, "Why?" He says, "Because the other people don't want you here." I was like, "Why?" The guys says, "Well look at you." I was like okay look at me. He made me feel so bad it took me another 20 years if I ever went back to a pool. There's a stigma when you have something on you people look at you totally different when you're covered in scales. They really look at you differently.

Even with the drugs that are out now, they're great, the drugs are out but I still am not clear, but they hep me with the arthritis part. I'm able to function, I'm able to walk, so I do a lot better. I like giving back I like talking about the disease, because at one time I wouldn't even say the word psoriasis. I didn't want to talk about it, didn't want to share my story, but now I'm getting a little better. I want to give back.

Johnathan : Let me ask you this is what- again I was so certain to have this story and have it first, and really for this reason. As you just talked about there's teasing and bullying which we'll talk about later on tonight. The healthcare system told you- didn't know what you had. The doctors didn't know what you had. Hospitals didn't know what you had. You've lived through a time of this enormous understanding and then this advance, and that's your gift to us.

You went through that for us. We stand then on that patient experience. We hear this voice. Let me ask you then, because I heard this, there was a long time you said you wouldn't talk about it, wouldn't share. Then there was a day when you began to want to do it. Talk about that. I want to hear about the first day you thought I can share my voice.

Diane Talbert: I got what's called erythrodermic psoriasis. Erythrodermic psoriasis I was 90% covered in psoriasis. Your skin actually falls off. I could lay down in bed, wake up, and I got see the outline of my body. I looked like something out of movie. That's how bad it was. I went to my dermatologist my dermatologist looked at me and says, "I don't know what to do for you. I don't know what to do." I went

to my primary care physician and she says, "You need to go to the hospital." In my mind I'm going if my doctor can't help me doesn't know what to do why am I going to the hospital?

I actually went to three dermatologists and one we- I actually found one. One dermatologist who says I can help you. When we went he prescribed all the drugs for me, and then we went to the insurance company. The insurance company says, "No You can not get these drugs to help you. I don't care if you can't walk. I don't care what you can't do. You can't do this drug, but we will give you this other drug" that didn't help me for six months. I did take another drug-

Johnathan : Hold on one second. I know you're on a roll, and I want to hear that roll. I just want to take one moment. All the experience and all that you went through three dermatologists, sent to the hospital, not go to the hospital takes a brave person not to do that. Someone said, "I can help you and could help you." Then you couldn't get the medicine that a doctor prescribed you?

Diane Talbert: No, I could not get the medicine. They wanted to put me on a less expensive medication. We need you to take this drug first. Which I did, but the drug made me sick. It made me even worse than being erythrodermic, because I was tired, sleepy, I couldn't get up out of bed because of this drug. At that point that's when I decided-

Johnathan : You had things to do.

Diane Talbert: I got a job. I had a job so at that point-

Johnathan : That's a heck of a way to save money.

Diane Talbert: Yeah. At that point I decided that I need to do something to help myself. I can't lay here and feel sorry for me. That's when I called my doctor and go what can I do. We need to do something I pay my insurance. I had the same insurance company for 25 years, and I paid them never missed a payment. What can I do? That's when he said, "We can start writing letters." That's how we started fighting back. We wrote letters, he would write letters on my behalf, I would write letters. Then after six months they finally approved the drug. Every three months I have to go through this, because-

Johnathan : You still have to fight? You're still writing letters?

Diane Talbert: I still have to write letters.

Johnathan : They haven't had enough yet?

Diane Talbert: No not yet.

Johnathan : I wouldn't fight you six months. When you finally got through back up 25 years of coverage [inaudible 00:30:54] 25 years of coverage. You thought you were getting coverage I guess maybe not the case, but 25 years- yeah the golden anniversary of your coverage. 25 years then they didn't know you after that year 25, but then the letters, then the fighting. I wouldn't want to take you on. Then you break through, and now what every 90 days-

Diane Talbert: Every 90 days.

Johnathan : We go to bat again?

Diane Talbert: We have to write a letter, my doctor does, he has to write a letter saying yes she needs to have the drugs again for another three months. I just had my shot last month. They didn't approve it yet. Thank God he had some extra so he gave me a shot.

Johnathan : It's happening right now?

Diane Talbert: It's happening right now at this very moment.

Johnathan : Let me ask you has it made a difference to you? You look great to me. You're getting these treatments how have they changed your life?

Diane Talbert: Immensely.

Johnathan : How?

Diane Talbert: I can walk.

Johnathan : You can work.

Diane Talbert: I can work. I'm not in pain, I'm not flaking everywhere. It makes a big difference with the drugs.

Johnathan : If you stop taking it what will happen?

Diane Talbert: I'll be in the bed. I won't be able to work, I won't be able to do anything. I'll be in pain. I won't be able to walk up a set of steps without the drugs. I really need my drugs.

Johnathan : One thing you said up there that I'm never going to forget is giving back. We hear that word a lot, but to me it's from a person who hasn't endures so much to want to give. I asked you the first time you thought about this the first day. All this time you've had to endure. Hard to give when all you're doing is enduring. What's driving the last part for you to come to this person, and that person, and here tonight, everybody here where does that come from?

Diane Talbert: I don't want anybody to suffer like I did. I suffered for years by myself, by myself with this, with nobody to help me. If I can help just one person to get through what I did I want to give back. I want to speak as much as I can. I want to go places do things. I just don't want anybody to go through what I went through, and I don't want them to ever think- people to think they're alone or by themselves. There's always somebody out there that can help you.

Johnathan : The last word is this. When we were talking and you had explained your story, and your strength, and your spirit we want to talk about a word that we don't always try to capture in these when we're fighting when we're striving like you, and winning, and that's value. We talked about what a voice of value is. You're experience is one, but your voice is the one that's cutting through. You are connecting. You have helped other people. What is your voice you think connect to and mean to them?

Diane Talbert: You're not alone. I'm here for you. If you're having a bad day call me, because I know I've had bad days. I can get you through those days. I'm always there. I've helped a lot of people. I started a support group for my area. The people they call me 12, 1 o' clock in the morning. Especially teenagers, because they just don't understand. They call crying. I can get them through that, and somebody says, "I don't feel like living." I can tell them, "Oh yes you do. You'll be fine." I can get them through a bad day. I'm glad that I can be that voice for someone else.

Johnathan : You make our day, you make our night. This is the amazing Diane Talbert.

Diane Talbert: Thank you.

Terry Wilcox: Karissa is here. Karissa's here.

Johnathan : Okay.

Terry Wilcox: Here's Patricia she's actually ready to go and make sure you thank Global [inaudible 00:34:38] at some point.

Johnathan : Okay, just bring her up?

Terry Wilcox: Yeah she's right there.

Johnathan : Oh okay. You can see through my- some of my expertise comes from [inaudible 00:34:58] talk to and then I have my notes. We have an expert here to tonight. This is a nurse practitioner, and I've met a lot of nurses. They're all spectacular in their ways. Nurse practitioners are ones who have special skills, and they have special knowledge. They are the ones who do lay, honestly like doctors, they lay their hands on patients too. They are the ones that they need. They are part of that thread between patients and their care. This is Karissa Tovar Dalmata. Thank you very much.

We've shared a lot of information tonight about psoriasis and about the patient experience. You're the one who sees it from the other perspective. You see the patient, the diagnosis, the treatment, the experience. These people are looking to you. They sit in a chair like this, they've walked the patient journey, and then they arrive with you. You know what they're experiencing, but tell us what it is that's really happening on the inside that'll make us understand and appreciate how the treatment works.

Karissa: Well usually I'm not the first provider that they've seen unfortunately. I try to make my patients feel good when they come to see me. Usually they don't know that psoriasis is not just a skin issue. There's a bit of education there letting them know that, that little patch on the leg that's not just the story of psoriasis. It's on the inside. It's an inflammation process. It is affecting your heart. It's affecting your lungs. It's affecting every organ in the body. More should be done that just here's a cream go home and put this on twice a day you'll feel better. A lot of patients that's still the response that they're getting from the healthcare industry. When they come to see me I spend a little time with them.

Johnathan : Let me ask you though you said that people are getting essentially mistreated by this. You said they hope they see you first, but often times they don't. What makes your perspective different?

Karissa: I think part of it being a nurse for 20 years, and seeing it. Seeing the changes in the therapies, seeing somebody who went from just topicals and photo-therapies to suddenly the systemics or the biologic agents, and sudden clearness. We sometimes would call that they got their trip to Paris. Now gone are the long sleeved, the long pants, the long faces, and we're in short sleeves, we're in shorts, we're in skirts, we're in heels, we're in happy, we're in makeup. We're enjoying life. Maybe we've lost 20 pounds, and we're enjoying being with our family, and enjoying life.

Johnathan : I can imagine it's made the great difference then enjoying life and not enjoying life. Let me ask you though in the time that you've been a- you said 20 years you've seen this.

Karissa: Yeah, registered nurse before I moved on to nurse practitioner.

Johnathan : You've seen this in 20 years. You've just walked us through a time when the best and highest treatment you could provide was the standard of care. Now we're in a different place. I understand that as innovation. In your hands you're talking about changing saving peoples lives.

Karissa: Right, psoriasis isn't a death sentence, but it definitely can shorten your life expectancy with the inflammation process running out of control over your lifetime. The short acronym that I'll give my patients are you won't let your car rev on three every time you turn it on. You'll take it to the mechanic and he'll

tune it down, and you'll be running at one where you belong. Some of these systemic agents that we can introduce to you in your body and your disease can put you running back at the RPM's that you should be.

Johnathan : People come to you for a tune up.

Karissa: Yes.

Johnathan : Often times we- it's something I want to talk about tonight so I can learn too is they call a biologic. A biologic is a special kind of medication. In your hands and your experience you've seen it develop and you've seen it then present. How do you use them and what are they?

Karissa: Biologic agents are different systemic medications. Meaning we introduce them to the body most of the time through injection. A small needle similar to a diabetic injection. It bypasses the liver function and doesn't get broken down by what we call the first pass affect. It's more readily available to the body. These biologic agents block different molecules from meeting up with their friends so to speak and creating the psoriasis cascade within the body.

Each biologic has its own little target. I usually just tell patients if psoriasis is a recipe of one through ten items and I remove one of them then the psoriasis recipe can not be completed. Each biologic interferes in that one through ten recipe in a different area.

Johnathan : There are a lot of classifications of biologic I understand. You said about the recipe one through ten. How do you determine the right treatment, for the right patient, at the right time?

Karissa: Unfortunately today I have to look at what insurance you have. They have some pretty strict algorithms that will keep me from maybe just choosing my favorite. Meaning-

Johnathan : Your favorite though I would define as that which you think will work?

Karissa: I believe all the biologics work. Some of them work better if you don't weigh too much. Some of them work better if you have a strong palmar or plantar psoriasis outbreak. Meaning your hands and feet are broken out. Some of them work faster, because you get more product up front. All of them have their own little nuances and I don't have any one that I would say has to be my favorite. The other consideration is the patient. Do they like needles, do they not like needles, how many times a year do they want to see me? Hopefully often.

Then there's like I said the insurance algorithm will play a role. Sometimes with certain insurance algorithms the patient has to try and fail three topical agents then I can order old time methotrexate. They wanted me to put a 27 year old on cyclosporine soriatane. I wrote back to them patient of child bearing potential I

decline. They thankfully told me okay, but this is the algorithm they have set in place, and they're sort of bypassing my ability to say you have psoriasis and it's really bad. You need to be on a systemic today.

Johnathan : They're not sort of bypassing it they are bypassing it. We call that the barriers to access. Let me tell you, you used the word algorithm. You mean a system of recommendations?

Karissa: Mm-hmm (affirmative).

Johnathan : A piece of paper somewhere that says your patient who I've never seen, who I don't know, who I've never meet, and I'm not a doctor, nor am I a nurse practitioner, and I am telling you that you will do this.

Karissa: Correct.

Johnathan : That is what you call an algorithm?

Karissa: Yes.

Johnathan : I've got some other words that we may be hearing a little bit later. You're talking about how you're getting around those barriers to access. Including being, as you've just said I want to make sure that you said, that you were essentially advised or directed to give a patient a treatment that could have caused them great harm?

Karissa: Like I said she was of child bearing potential, and one of them in particular if you have alcohol it would stain her body excessively. I didn't want to do that to the patient.

Johnathan : That is the wrong treatment for the wrong patient you're saying.

Karissa: Right.

Johnathan : Let me ask you then I want to also get this you said in something that I had a hard time believing. A couple years ago I might have said I don't believe it, but now I do believe. You talked about trying and failing. I've tried many things and failed many things. They weren't guaranteed to fail. Let me ask you, you said that you prescribed for a patient a particular treatment that you believed they need and deserve, and would help them, in your 20 year experience multiple years as a practitioner, then you said no, no your recommended or directed or ordered that an individual patient must try something that you don't think is going to work. If it doesn't work then they get something else. How does that work? We have all night by the way I want to let you know that.

Karissa: Yes, well I go into my zen moment. No, if I can help it I try to have my-

Johnathan : Let me just interrupt you a bit. I think people wouldn't believe that, that's what's happened. That's the first thing I want to get you to say.

Karissa: Yes, it does happen. They would like me to order what they want me to order. I don't want to order what they want me to order. I then have to take staff time to send an appeal, to send document ion why I feel my choice is the better choice. Sometimes I win. Right now for a particular patient I'm fighting over photo-therapy. How old is photo-therapy? Give me a break. You think I'm getting rich on photo-therapy? Let the patient have photo-therapy. No denied. It's tough out there, it's tough out there. I'm fighting for you I'm trying.

Johnathan : Getting better? Getting worse?

Karissa: If you have commercial insurance it's getting better. I have a few of the biologic agents that are saying get one denial and we'll give you medication. We'll just give it to you. If you tried to get the medication for the patient and you were told no we'll pony up the medication. I have another one that says get two denials and we'll pony up the medication. That's great if you have commercial insurance, but you don't want to know how many people I see that don't have commercial insurance. How do I get around the fence for them? For them there's a delay of six months, eight months, twelve months, or longer of getting them to the care that I feel they deserve, because I'm ordering the topical cream. They want them to fail, or doing the necessarily paperwork time after time trying to prove my point that the patient needs the care.

Johnathan : A lot of us sometimes use the word that patients are fighting. Sometimes they're fighting for their livelihood, they're fighting for their lives. You're talking about an entirely separate kind of war that's going on. You, the doctor, the patient, the insurance company what I'm asking you is can we get to a place where the patient can only be fighting one war at a time instead of a separate battle?

Karissa: I try not to take that battle to the patient if I can. Somebody has to fight the battle and I don't know if it's all of us together collectively as healthcare providers, or all of us a community, as a village not even necessarily people with psoriasis. I'm sure this is going on in every difficult disease to treat that has expensive medications. I'm sure it is. Until we put our foot down and say this is not the way to treat people and their healthcare issues I don't know what's going to happen.

Johnathan : Well help us put our foot down. Put your foot down by raising your voice. I'll make this last point that I need to ask you. It must be so easy not to pick up that phone, not to wait on hold for an hour, to go on to the next thing. That is preventing you from doing this other care for what you live for for what you serve for. I want everybody here tonight to know about all of the distance and extra space that you go, the extra time, the extra effort, and what you have to endure too.

There are people who are fighting the patient fight right along with them who we do not hear sometimes about, and who we can not think about, because they are in some ways the hidden fighters. The one last point I want to say is this is a voice of value as well. Do you think or do you know that your voice, their voice, this one of value can win the value argument and change the balance of power towards what you can recommend and treat? Rather than an algorithm as you put it.

Karissa: Well that's why I'm here tonight. That's my prayer. That's what I'm working for.

Johnathan : We're honored to have you here thank you, thank you for being here.

Dave Cuttler: I'm at a loss that in this day and age that my doctor and I really have to fight with an insurance company to get what I'm [inaudible 00:49:20].

Diane Talbert: [inaudible 00:49:21] a better quality of life. [inaudible 00:49:26] [crosstalk 00:49:28] the patient [crosstalk 00:49:34] for you and [crosstalk 00:49:41] sometimes life can [crosstalk 00:49:44] diminish my quality of life, and it did. Every three months [crosstalk 00:49:55]

Dave Cuttler: If the insurance company would listen to my doctor I don't think I'd ever come in with a bad day. I would walk around [inaudible 00:50:12]. I wouldn't have to put my hand down in the chair seat to get myself up. [inaudible 00:50:21] to get everything in the restaurant and get on the floor, be in the back, be wherever I need to be and make it a success [inaudible 00:50:29]

Johnathan : We're going to hear a little bit more about, that's a friend of mine named Dave Cuttler, and here more about him. A little bite of his experience. I'm going to bring up a special friend, and a new friend, special patient, and a special story, and I want you to make him feel extra welcome. This is my friend Eric Boudreau. Eric you're hear tonight as everyone here tonight. It's not just to share your story and to give. Your voice has the value that we're looking for.

I heard your story, and your experience, and your drive. You're the kind of person we have to hear from. You're the kind of experience that is what is happening out on this ground. Eric let me ask you the first thing. Tell me how long, your patient story, how long has as a psoriasis patient- How long have you been a patient, and what characterizes you mostly as a patient?

Eric: I've had it since I can remember. Since as really as I can remember like wearing shower caps with creams on my head when I was a kid, and my finger nails falling off. I didn't know what was going on. Just being as far back as I can remember pretty much.

Johnathan : All your life as a psoriasis patient, and all the bad that goes with it being a young person. To me you're a person who takes care of himself. This is a standard comedian as well. This is a wicked sense of humor, you get him going. You're

driven to live your life. What is it you most want from treatment that will help you do?

Eric: To be able to keep working basically. I live alone and I don't make a lot of money so I can't work it's a big deal. It's going to affect me tremendously. I really want, out of treatment, is to be able to keep working. I don't even care about my skin. My skin is cleared up. It's just basically to keep where I can-

Johnathan : The treatment has helped you.

Eric: Yeah.

Johnathan : The reason why I insisted to bring forward Erik is because I said before with everybody here especially the nurse is how easy it is not to fight as hard as you are. How easy it is to walk away and say that you might not be able to walk. These treatments are going to be the difference between allowing your heart to drive and let you work or not. What makes you want to work? What makes you want to keep going? Why are you so damn driven that way?

Eric: There's no other choice. I live alone. I have to work. That's how I was raised. I've woken up and not been able to walk before. I've woken up and tried to go to work and I can't put my shoe on, because my foot's so swollen. I have to call into work.

Johnathan : You're battling through. You're doing a set of treatments. Let me ask you, you are on certain treatments, blood work, anti-inflammatories, you're being given some access, but there are things that you still need that can help you, that you're not getting. Talk about that a little bit.

Eric: Yeah I mean I need regular blood work and the treatment. There's copays and stuff, but on top of that it's leaving work early or missing days. You wake up, and like I said, you could just wake up and feel like you have a severely sprained ankle and you can't even walk. I woke up and my knee was blown up. I had to go to the ER I couldn't work for a week. The uncertainty of it you never know. I could wake up tomorrow and I won't be able to go to work.

Johnathan : What does your doctor tell you?

Eric: Not much.

Johnathan : There's so much that isn't know, but let me ask you-

Eric: I like the nurses better. They're not walking out of the room before I can ask them answer to answer a question.

Johnathan : I know a few nurses I can help you with that. Let me make this point that you said to me that really struck me is that not knowing what the next day would

bring. You're a person, you go to sleep, you intend to wake up, you intend to go to work, take care of yourself, and support yourself. You're saying that because of your condition that you don't know if that will happen the next day, but you're driven to make it happen.

I wanted to bring Eric's story forward because I've met courage and I've met determination, but this is one that I think we haven't thought as much about. Like I said it's the way you were raised, it's the way that you're showing us, but your desire to work is greater than your desire to be comfortable and your desire to endure this. I'm interested to hear from you and to have you then teach us that there is dignity in your experience. I think as a patient that is your voice of value and the way you were raised that's a voice of value as well. Are you able then, do you think, to have the system help you and believe in you to where you can give back in- we call it the value of innovation. How about that?

Eric: I don't know what the question was [either 00:56:54].

Johnathan : What I'm saying Eric is-

Eric: Can we cut by the way. Cut to commercial.

Johnathan : What I mean to say is-

Eric: Too complicated for me.

Johnathan : No, what I mean to say is people look at you as somebody who's costing the system a lot. By working and supporting yourself actually honestly you're the one giving back. You're the one so it's not just the dignity of it all-

Eric: I'd rather work yeah. It's just how I've always been. I don't want to stay at home I'd rather work.

Johnathan : That is the great gift too. That keeps the system going. All of the fights that we're doing we talked about earlier frameworks that look upon you as expensive. The fact is you're giving back. You're life is one of dignity. You're the one making money. If you work your [inaudible 00:57:55] you're the one giving back. We've got to keep you working. We've got to keep you living, and got to keep that spirit strong. Please thank Eric. Thank you.

Erik told me about so clear and his desire to work was this to some people in the system, I think, they look upon Eric and think that he's expensive. They look upon Eric they think that he's a person of cost. That isn't true, that isn't true there is a- To support him, to let him live his life makes this country rich, and makes our system rich. We call that the value of innovation. The longer that we can let him live his life of dignity and work the benefits we have will be not just ones of human dignity, but are overwhelming in the financial scheme. I learned that from our next speaker. I tell you these are complicated issues, and they're

ones of detail. When I need to know something I pick up this phone, I make one call to this man, the doctor of healthcare economics Dr. Robert Goldberg.

One moment then about- before we begin and get to you so much. I want to take a moment to see that I look upon my friend Eric as one of a million patients. There's a million parts to that life, to that heart, to that human. It is based also in the fact that he to this society he's priceless in that way. You're the one that taught me that. What makes him priceless.

Robert Goldberg: Well I think what Jerry Mathers said, and by the way I had a crush on Ms. Landers too.

Jerry Mathers: Everybody did.

Robert Goldberg: Yeah I know. I still do, but it's been years of therapy to get me off the- To that point what's the value. We're talking about two visions of what healthcare is for. We have one vision that is articulated by this group ICER which the way to describe them is-

Johnathan : Keep it clean. Keep it clean.

Robert Goldberg: I will, I will. They want to be the good house keeping seal of approval for what is everybody in this room's experiencing in terms of denials and stuff. They're arguing that, that approach makes innovative medicines affordable to patients and to the insurance system. Let me peel back the layers of what all that means to let you know that ICER calculated that; Because new medicines are more cost effective, and because they get discounts from the insurance companies to cover some drugs but not others that a \$33,000 a year treatment cost them, with all the costs to them, \$13,000. That's step one.

Step two is they turn around and charge you 30% the retail price. Then to add to the enjoyment, if you will, they then limit the number of people who will get access to new medications. Which means given the data that I've looked at Jonathan, because there's a higher incidents of mortality associated with even a year use of methotrexate. There'll be, over five years, an additional 77,000 life years lost by capping how much we spend, because they're concerned about your health. That's one vision.

The other vision is one that we talked about from Matt Damon's water project which is Matt Damon has a project to put running water in African Villages. Many, many people in the world still don't have running water. I have running water. I still don't use it, but that's a whole other question. Bourbon is much- Somebody asked one of the children who finally got running water what it meant to them. He was a nine year old boy. He says, "I spent everyday going down to the river bringing back water. Going back to the river filling it up, bringing water back. I no longer have to do that. I can now play with my friends. I can now go to school. I want to dream to be a doctor.

Hope is not just a sentiment. It is a capability. What my vision of healthcare is, is to create hope which allows us to continue to keep moving forward. That's all their is to it. Anything else is not healthcare.

Johnathan : I admire the field of healthcare economics even if others don't. The reason why I think it is so vital is this. I can remember the first time we ever talked about this. I said, "Well what they're saying of course Bob is that if we spend less on patients we will save money." This man came out of his chair. If you want this man to come at you. What I mean by that is what you articulated then to me is really ground breaking that a lot of people haven't heard before. Your point is to invest in patients has a return that it's enormous economic return that is almost incalculable and makes the case ultimately that it's the easiest call of all.

Robert Goldberg: Look there's a prosaic part of it which is ICER said, "We shouldn't spend money on people with psoriasis, or hepatitis C up to- We can only spend a certain amount and we should use the cheapest drugs first, because we have to pay for roads, and bridges, and teachers, and so on." As an economist I said, "Wait a minute. Who's going to pay for those roads and bridges if not the people that you're denying access to and who's lives you want to shorten?" It is the most counterproductive short-sided thing you want. It goes back to my original point which is hope is a capability. Work is dignifying, or endeavors are dignifying because it allows us to do things with a freedom that we have.

Believe me I had acne in high school. I was in a state of poverty then. Actually I had eczema for a while. I couldn't go to school. To have that cleared up gave me a sense of purpose and a sense of belonging once again. True maybe you can't calculate it, but it's still nonetheless invaluable. You can't have a society, you can't have progress without it.

Johnathan : We are essentially having an argument over the word value. Which is why we speak to what the voice value must represent. You laid out to me is it is an argument between a static number of how patients are too expensive, and the unimaginable incalculable way that they build and benefit society. Are we still having that fight? Is the hinge turning?

Robert Goldberg: Yeah, so here's the thing if the insurance industry was running Smith and Wollensky's their business motto would be to keep you out as long as possible, and only serve you the food that was three days old. Now what kind of business is that? Do you want your health care being delivered by people that would run a restaurant like that? Their definition of value is what it takes to maximize the prophets they make from you. That's really what this all boils down to ladies and gentlemen. The reason when you go to a car dealership the rebate goes to you as a customer. If Donald Trump is going to get a rebate on cement it goes to him. If someone told Donald Trump or even one us, "Well that rebate's going to go in my pocket and I'm going to charge you 30%- the full price" that's how insurance companies are making money today.

It is the biggest source of cash that they're generating. 150 billion dollars of value that should be going to us in lower prices, and immediate access, and better health is going in the pockets of insurance companies. Look I'm a free market kind of guy, so it pains me to even talk like those terms, but that's the fact. We need politicians and we need legislatures to take action. We need lawsuits too, I hate to say it, to change this. If we were AID's patients this wouldn't stand. This wouldn't stand, but because you got psoriasis, or high cholesterol all of a sudden that's not a real disease. That's bullshit. I'm sorry. Do I still get dessert?

Johnathan : That's the longest I ever heard him go without cursing.

Robert Goldberg: That's true. That's true.

Johnathan : Look break it through for us. Hold on a second you are saying that a psoriasis patient isn't winning this fight?

Robert Goldberg: No.

Johnathan : Another kind of patient is. How then do we understand then that all patients have Voices of Value and how does that voice breakthrough?

Robert Goldberg: Well first of all one of the reasons I'm here is I want to help. I want to help all the people that are working for other patients and for themselves to get that message. In terms of communication and translate it to their- I will help translate it to their politicians, to their legislatures, to their friends and family, to let them know that companies are making money off of your sickness. Where else in the world do you say, "Well I come in as a patient and the rebate that I generate, because I show up as a patient doesn't go to me. It goes to some insurance company." That's wrong. The only reason we can do it- people ask me how did it happen? I said, "Because we let it happen." Like lots of injustices in this world.

Johnathan : Where can that go? You essentially have a ground breaking theory. That the rebates that are given to industries insurance, pharmacy they can go where do you think?

Robert Goldberg: They can go to patients. What a novel idea, right? The discounts go to us. Again I think if enough of us start speaking and talking. Let me tell you something it's not hopeless. When I did that little video two years ago it was part of a longer term strategy that you and I had been working on to basically get people to begin to take a very complicated issue and realize that they're being scammed.

Now the rebate issue is on the national agenda. It's in the gun sights of your employers, it's in the gun sights of the legislatures and the gun sights of the department of justice. We are there we just have to keep the pressure on. My goal is within a year is to eliminate the rebate ripoff and make sure that people

get the right drug for the right treatment all throughout their lives. That's what we're paying our premiums and our copays for.

Johnathan : I'll drink to that. Finally because of so much that we talked about from ICER, and what you called the value frameworks, and the war over the word value, and the fight that resources are so scarce, and limited again I want people to understand that you pronounced a theory not just a believe. A finding that to invest in patients to get the right treatment- You said as a human dignity and as a personal principal that patients should have the finest access. Your point is it's all that can save them physically, all that can save us economically.

Robert Goldberg: Our longevity, without going into the next video I'll do, living longer is the greatest source of prosperity and well being we've ever had. Again it goes to the idea that once in the 15th and 16th century when people started living longer they realized that they didn't have to prepare for death by accepting the order of the king or the rule of a church. They could plan for themselves the concept of happiness emerged. That sense of dignity and happiness has spread throughout the world. That impulse that capability is something that is not only important, but what health innovation does is it makes hope more affordable and more available to individuals.

When people say, "We can't afford new medicines" I say, "No, no we can't afford not to use new medicines." New medicines and new technologies are what make living life better, easier and more effective. Again the reason we seem to be paying more for it is because the value that these advances are being generated are not going to us as individuals. That will change. I still find it amazing we're here in this beautiful room which looks like my bedroom actually except ...

Johnathan : With all the liquor too.

Robert Goldberg: With all the liquor too yes, yeah. For all you ... Anyways for all that the fact of the matter is that these medicines make a substantial difference in our ability to stay afloat. If we were treating psoriasis like they're treating it 25 years ago where the average stay in the hospital was 17 days, and there was pronounced loss of productivity, and the isolation, and the loss of dignity. Think about it in terms of HIV or tuberculosis what will the cost of treating it with other kinds of treatments be? Is a 20 year old Chevy good as a Chevy today? I don't think so. There's a qualitative improvement in health care that we're not getting the maximum benefit for.

Johnathan : This is a man for patients who has your back. Everybody Dr. Bob Goldberg.

Dave Cuttler: I was diagnosed with psoriatic arthritis in October of 2004. You know it's not a sharp pain. it's a dull- you know when they stick a dull knife in you. I just put on a smile and grin and bear it. I walk my restaurant all the time, I sit down with my

customers, I work through it. We started with the medicating which is a IV infusion-

Female: You're next Johnathan's [crosstalk 01:13:47]

Dave Cuttler: -type scenario where it's done in his office. It takes about four and a half hours every six weeks. It was very, very successful. Getting out of bed easy, bend over, no restrictions at all. I made my appointment, his office called me, and said to me, "David your insurance won't approve six weeks. They want you to wait eight weeks to have your injection." As I get further away from my infusion it's definitely harder to just do regular things that I love doing at work and need to be done. I don't want anything extra. I just want to be able to have a great quality of life.

Johnathan : That's the story of, I said, a friend of mine name Dave Cuttler who couldn't be here tonight. I wanted to emphasize again what said and it shows, I think, how small differences can make enormous changes. I never knew he had any condition at all. This is a big man. This is a strong man. You see the spirit. You see what a large personality he is. He told us that, like he said, he was getting infusions every six weeks totally living. No affects, turned his life around, taking care of his father, taking care of his family, working like he does, successful as he is. They went to eight weeks.

Seems like perhaps not perhaps doesn't seem like a big difference. Seems like yeah we gave you six weeks, but we'll change to eight weeks. I'm not a doctor it doesn't sound monumental to me. It has absolutely changed his life for the far worse. That is an adjustment that has taken a mans life and turned it absolutely in the wrong direction. Those two weeks, that number that went from six to eight, has taken that human being, an independent successful person, who a lot of people rely upon and made him less able. Not just less able, but I think unable to do the things that he is used to being to used to doing, and used to living.

I make the point that I wanted to speak to him. Like I said he could not be here tonight, but that voice is one that we're not hearing. That voice is one that I think we're not understanding. I want to bring another voice up here today for another similar experience that speaks to how small changes- seemingly small changes and small policies can literally affect a life. This is our new friend Dani Yevsa, please welcome.

Dani Yevsa: I know what you're thinking, but I'm not covered because of psoriasis. I'm actually an orthodox Jew. I'm a rare person because I have psoriatic arthritis without psoriasis. My situation was a lot different than most of everyone else that you've heard, because I was told by my doctors for over 11 years that nothing's wrong with me. It wasn't until I had my second child in a two year span, no judgment, that I couldn't move anymore. I was in bed for two months.

Johnathan : Describe a lot of years. You said they didn't understand what was wrong with you. How many years was that going on?

Dani Yevsa: Eleven.

Johnathan : Eleven years.

Dani Yevsa: Eleven years. I'd go to the doctor-

Johnathan : In pain?

Dani Yevsa: Absolutely. I was in high school and I was in varsity tennis. I was able to do [crosstalk 01:17:53] a lot. I was the president of the Student Counsel and I had to drop out of college, because I was in so much pain I couldn't write my notes. I couldn't continue to take the classes at the same rates that I had been. I'm still in college actually because of that. It's been a long time, and maybe eventually I'll get my degree.

Johnathan : Let me ask you, so you were unable to be clearly diagnosed, but eventually you were.

Dani Yevsa: Yes.

Johnathan : I came to know you through- this is a published author I'll have you know in the New York Daley News. I've been published a lot of places. I've never been in the New York Daley News, so this is my new literary agent as well. Here's my larger point. The point is the headline of your piece, and again there's jealousy involved I understand that, "Denied the Drug My Doc Prescribed." After all the years of pain, and dropping out, and then diagnosed, and then a treatment path. A path forward away from the pain prescribed a medication couldn't get it. Doesn't make any sense to me.

Dani Yevsa: I can't tell you how excited I was just to even be recommended to go to a rheumatologist. I'd never even heard this terminology before. What's a rheumatologist? I go and she's like, "Oh I know what you have." I'm like, "Great fix me." She's like, "Oh well actually we can't." I said, "What do you mean?" She's like, "Well I know what I want to prescribe you. I know what I want you to go on, because there's a brand new medication, and it's going to change your life." I was like, "Great I'm ready."

She's like, "But first we have to put you on this medication that was developed about 50 years ago and probably won't work." I said, "But why do I have to go on a medication that probably won't work?" She said, "Because your insurance won't allow you to take the new medication. It's just too expensive." I was like, "All right I'm flexible. I'm nice. I can deal with it."

I've dealt with it for this long. It was so bad at that point that I couldn't walk without a cane. I'm 33 years old today, and I have been dealing with an actual diagnosis since I was 30 years old. I couldn't walk without a cane. I had two children under the age of two, and I had to have a cane. I don't know if anyone else has tried to push a stroller with a cane. Not possible.

Johnathan : This process that you're describing, which was I know what to give you I think it will help you put the cane away, can't have it. Try this first. It's a process that is called step therapy. When I first heard it, it didn't sound so bad to me. Step therapy is essentially Dani's here. We want to get Dani here, so there's a step in between and if you step there and doesn't work you get go. Well wait a minute it didn't work. I just want to say we've all been prescribed some medications. I've never been prescribed anything that somebody thought wouldn't work. You are saying that in between your pain and the possible cure was something that your doctor said, "I don't think it's going to work," and yet you had to take it.

Dani Yevsa: Yeah, not only did she not think it wasn't going to work. She had to put me on opiates and steroids and all these other medications, because she knew it wasn't going to work. I gained 75 pounds, and that made it worse. It was harder to walk, it was harder to move. The medication made me sicker. In fact I was on four different medications before I was actually able to get the medication that my doctor originally wanted to prescribe me when I first went to her office.

In that time period I lost two jobs. I could not work. My employer just said you're missing too much time. When my immune system was shut down, because of the medication I would pick up every sickness that I came in contact with. I live in New York City people come on. I'm going to catch everything. If my neighbor sneezes next door I'm getting it. I ended up losing two different jobs and because of that I lost my health insurance. My husband lost his job, because who had to take care of the kids? I couldn't I was in bed. We ended up on Welfare and Medicaid.

I'm a junior accountant I was making \$60,000 a year. My husband has a Master's degree in linguistics he's a professional translator. We together are productive members of society, but neither one of us could work. I had to do that for two and a half years, before I could get my medication. I was walking with a cane until last year. Today I walked to the stage by myself.

Johnathan : Jumped on. This process that is described to us we call the theory of step therapy which I guess might you know put it down on paper it could make some sense. People don't believe sometimes, and the advocacy community wants to talk about this. This is wrong we think that this is a mistake. A lot of times I think they don't believe that a voice of value like yours exists. All of the things that you said that I think are hard to believe for some people they have to start believing it.

That is why people say step therapy- we say fail first. You must fail, fail first, fail second, continue to fail, to get sicker until this happens. The big point the reason why I think that what you wrote was so profound not just in a telling, but in it's timing. 40 states in this country at a time when we're maybe do we agree on anything politically, 40 states have agreed on one thing. That is that step therapy will be banned by law.

Dani Yevsa: I actually participated in getting it passed in New York State. I lobbied in Albany, and I spoke with several senators, and if I might gloat a little bit my name came up a couple times. Because of that I know that this genetic disease is not going to have to affect my children the same way that it affects me, and my sister, and my mother, and my two great aunts who also have autoimmune diseases and have to deal with medication on a daily basis. My kids might actually be able to grow up and not have to deal with fail first, and get the medication they need.

Johnathan : That's the finest and most dignified lobbyist I ever met. I want to let you know. Make a point them when you were telling your story and you're recommending to public leaders you changed their minds. You reached them and changed their minds. How did you do it, and what did it look like when you were doing it?

Dani Yevsa: Well it looked like a lot of cameras and it was very loud. The whole process is memorable to me. Mostly because I was able to finally tell everyone what I personally had gone through. I had gone into just thinking that my doctor is who's going to be taking care of my care. That my doctor, this wonderful rheumatologist that I finally found who says you actually have something that I can cure, she can fix it. I didn't have my doctor in control it was my insurance who was making those decisions for me. To be able to go and speak to someone who can actually change a law that will allow that insurance company to have restrictions, so that they can't put on limits to anyone like me's ability to get the medication that they need that made a difference. Not only in my life, but in other peoples lives.

Johnathan : They changed a law, you changed a life, you changed thousands of lives. Thank her, Dani Yevsa. [inaudible 01:26:42] When's Stacey up?

Female: Stacey [inaudible 01:26:50]

Johnathan : We're going to have a good time tonight, and you're going to all take over now all of this hard work. The reason why we had you download the system is because now we need to hear from you, and all of you. What we're going to have here tonight are a series of questions, and you've already got the cash prize, so it's all for you. What we want to do is we need to hear not just from you and what you think, but what is inside you as well. There are questions then of your value of your feeling, of your judgment. These are questions that we all need to ask. Joining me is- come on up here it's okay. You come on up here. This is a friend, this is a teammate. A little closer my God. This is a superstar. This is my friend the legal eagle, and she's leading this. Please welcome Stacey Worthy.

Stacey Worthy: Hi everybody. Thank you for having me, and Johnathan thank you for such a wonderful and informative event. We've heard a lot tonight about value, and what treatments mean to you individuals personally. Right now what we want to do is get you all engaged and use this poll. If you have your phones pull them out. Earlier on we had you text 22333-

Johnathan : Anybody not have it? Everyone have it? I'm going to know if any of you are not doing this. I want to let you know that.

Stacey Worthy: Where am I pointing.

Johnathan : I'm sorry text patientsrising P-A-T-I-E-N-T-S rising to the following number 22-

Stacey Worthy: 333

Johnathan : 333

Stacey Worthy: Yes, it looks like this is not working.

Johnathan : This is not hold on.

Male: There's a power button on the corner there.

Johnathan : Top corner.

Male: Top left side power button.

Terry Wilcox: No.

Johnathan : It's not responding.

Terry Wilcox: Can you go to screen one?

Male: I'll change it.

Terry Wilcox: Yeah, okay.

Johnathan : This is live television I want to let you know this.

Stacey Worthy: Got it. All right so with your phones ready the first question is true or false patients respond differently to different treatments. What works for one may not work for another. Therefore they must have access to various treatments for their condition. If you believe this is true text A. If you believe this is false text B. I think this is a no brainer here. We got a lot of trues.

Johnathan : There are some things that are so true they are true greater than 100% I want to let you know.

Stacey Worthy: Yes. All right next question we've talked about insurers and independent organizations interfering with patient access. Who do you think should have the final say on which medication a patient takes? Text A for the doctor and patient. Text B for the insurer. Text C for an independent institution.

Johnathan : There are no wrong answers we need-

Stacey Worthy: Yeah, feel free to choose whatever you believe.

Johnathan : Hold on a second what I want to say is we must hear from you. Honestly this is a value as well. We want to hear input and we learn as well. We must here from you.

Stacey Worthy: Yeah. Okay next question.

Johnathan : I will be asking 3% of you to leave at this point. No, no, no, not just that but the reason why these questions are meant- they will get more interesting in differentiation is there is a lot to say. We need this feedback to not just listen, but to learn. Later on there are questions to which there are many answers.

Stacey Worthy: Mm-hmm (affirmative) yes. All right third question. We've heard a lot about value frameworks today. Do you believe that fewer medications would be available to you if value frameworks were used to determine whether patients could access their medication or not? If you believe this is yes text A. If you believe this is no text B.

Johnathan : Very interesting.

Stacey Worthy: Yup. A lot of movement there. Okay this is a fun one. What does the word value mean to you? You can go ahead and type your answer in. It will pop up on the screen. It will be anonymous so your name's not going to be attached to it, but it will show up here.

Johnathan : Look at that.

Stacey Worthy: Yeah. Patient access, something important, quality of life, effectiveness, I can work, benefit, being heard, safety, access to drugs.

Female: [inaudible 01:32:18]

Stacey Worthy: Yankee's as world champs. We're clearly in Boston. I mean not in Boston. I'm a person. These are really, really impressive answers. As you can see value means something different to every person. Okay we're going to switch gears here a little bit. Going to ask you some more questions, but they're going to be a little bit of ethical questions. We do anticipate that there will be varied answers. Feel free to choose true. Feel free to choose false.

First question true or false I would be willing to give up one summer vacation family so that an immediate family member could feel comfortable wearing a bathing suit? Okay next question. True or false I would be willing to give up eating out at restaurants for one year, or actually I think it says six months up here, so that my child would not be bullied by his or her classmates about his or her skin.

Johnathan : I feel bad for Smith and Wollensky at this point. Fascinating that number was different in another city. I want to let you know that. What a wonderful crowd I have to tell you.

Stacey Worthy: Yeah, very altruistic. Next I would be willing to downgrade my mobile data plan so that a coworker would not constantly feel itchy. Coworkers don't matter as much I guess. Yeah, we all feel pretty passionate about our data. Okay, next question I would be willing to keep my used car for one more year rather than buying a new car so that my closest friend would be at a lower risk for a heart attack. Okay, and last question I would be willing to use a treatment that saved me a \$100 per month even if there's a chance I could get skin cancer from that treatment.

Johnathan : Hhmmm.

Stacey Worthy: Okay, great. Well the reason that we did this exercise here today is to show that life is full of trade offs. You have your own sense of value, and what you're willing to pay to provide value to your self, your loved ones, your family members. That's a decision that needs to be made personally. You may be willing to spend more if it means your getting that medication that doesn't have a risk of cancer. That's a decision that needs to be made by you. It shouldn't be made by an institution or by an insurer on your behalf.

Johnathan : Please thank Stacey's poll. The Stacey survey I call it is one that lets us dive in deep. Your organization called the Aimerd Alliance stands for what?

Stacey Worthy: It's the Alliance for the Adoption of Innovations in Medicine.

Johnathan : The alliance for the Adoption of Innovations. The first thing we talked about almost tonight was what innovation means and what it is it can do. The thing that you [inaudible 01:36:52] as an attorney is that you said that you have seen, in the time that we've worked together, you've seen a shift in the balance. In some ways away from the patient interest and regulatory and legally in ways you think are hurting them, blocking them in ways that we haven't seen before.

Stacey Worthy: Yeah, so we've heard about this tonight. We've heard about step therapy. We've heard a little bit about prior authorization which is a policy that insurers use to prevent you from using a medication until you get their approval. They have to decide that the medication is medically necessary. That term medically necessary it implies that it has a treatment aspect to it. They determine that it's

medically necessary based on how much it costs not whether it actually treats your disorder. We've seen non-medical switching.

This is a policy that insurers use to- you have a stable patient. A lot of times patients with psoriasis it takes quite a while for you to achieve stability, because you're trying so many different medications. A lot of them may not be effective. A lot of them may have really bad side effects. Finally you're stable and you're comfortable. Then the insurer forces you to change your medication, because they're either dropping the medication from the drug plan, the formula all together, or they're making it more expensive and then the patients can't afford it, so they have to change their medication.

Johnathan : People talked about arguing and writing letters. You're talking about essentially a legal approach. I think you're opening a different avenue around, and through, and beyond these barriers to access, the legal approach.

Stacey Worthy: Yeah absolutely. These strategies that insurers use can violate state and federal laws. At the federal level we have non-discrimination provisions under the affordable care act. At the state level there are consumer protection laws, and as we heard today now step therapy specific laws. Patients can come forward and they can sue. They can get access and they can prevent insurers from using these policies moving forward. We are seeing this and it's been very helpful.

Johnathan : My point is breaking down what we can do how does it- you can stop one problem you can target one thing. You're talking about something that's much larger than that, that encompasses the patient interest, and makes possible the patient voice.

Stacey Worthy: Yeah, so right now we have a website called [coveragerights.org](http://coveragerights.org). It will explain to you how you can take each individual step. If you start off with talking to your doctor, working together to appeal the denial of treatment. A lot of times for the majority of patients that's all it takes is going through that appeals process. You'll have access to that medication. If that doesn't work there's another step you can ask for. An external review which means you can have an independent organization outside of your insurer determine whether you're insurer made the right decision. If that doesn't work then you can file a complaint with the insurance commissioner or the attorney general. Our website [coveragerights.org](http://coveragerights.org) is state specific. It will give you instructions on how to go through that process all the way up to the complaint step.

Johnathan : The Aimed Alliance the Alliance for the Adoption of Innovations in Medicine that is an enormous contributor to the public [inaudible 01:40:24] but you have said that the legal work that you do, the legal approach and the adoption of innovation they're not separate. They go hand in hand. How does one affect the other?

Stacey Worthy: I think it's really important to have those medications available. When you can't then you take the legal strategies to get access to those medications. That's how they go together. We've seen it. Just yesterday there was a lawsuit that was filed because an insurer was charging patients more for their medication for their copay than the drug was actually worth, or actually cost.

Just to put this into perspective a medication for an individual who did not have insurance was only \$5. The same exact medication for an individual who did have insurance cost \$25, so something's not right there. Insurance is supposed to be there for you when you need it. A copay by the very nature of the word means both parties are paying. Patients are speaking up. They're mobilizing, they're filing class action lawsuits, and we can change this.

Johnathan : We're here in Boston a site we believe may be of some, let us [say 01:41:36] issues, and some points of contention that the patient voice must speak to. You've just mentioned federal issues, state issues, sounds like a lot of frequent flier miles. My point is tell us why both approaches are necessary for the reform movement, and how we have to show up and really all 50 states and all places in order to get this done.

Stacey Worthy: Well, we have a lot of bad actors in the industry. I think the more avenues we have to go down the better. That means filing of suite at the state level filing at the federal level, but even going to your state policy makers as we heard earlier today. That gets change done. We got new laws passed, new regulations passed, even just writing up ads in the newspaper and getting your voice heard, getting it out there, mobilizing in any way you can. The more you speak up the more insurers are going to have to listen.

Johnathan : One of the things that you told me that I want to make sure we [inaudible 01:42:38] but not here is not just the aspect you know this person will sue you if she has to. The larger point I want to make is it's more than that. To add the voice, the perspective, and the one of persuasion, you're backed up by the law, you can talking about it as well. What you said to us is that of course there is a legal approach, but you've made the point really clearly that, that essentially is almost a last resort.

Stacey Worthy: Mm-hmm (affirmative)..

Johnathan : We can achieve these things outside of litigation sphere.

Stacey Worthy: Yeah, absolutely as I said it starts with a complaint and usually that's all- I mean with an appeal and that's usually all it takes. That's very simple when you're working with your doctor together just calling the insurer. It's an informal process usually at the beginning, and saying, "I need this medicine. This is the one that works for me. I don't want to go through the side effects," and sometimes that's all it takes.

Johnathan : My point is that a patient who's been through a denial, like I said, these people are fighting for their livelihoods, they're fighting for their lives, and they have another war to fight. You are essentially saying what? There is a path.

Stacey Worthy: Yes.

Johnathan : There is a way to victory. How do we see that?

Stacey Worthy: I think it's exactly what we're hearing tonight. It's speaking up, it's finding your voice, it's advocating for yourself. No one's going to do it for you. You have to be your own advocate. That's how you get heard.

Johnathan : This is the most dangerous health care lawyer I know. Please thank Stacey for this.

Stacey Worthy: Thank you.

Diane Talbert: [inaudible 01:44:14]

Stacey Worthy: Thank you.

Male: Good job.

Stacey Worthy: Thank you.

Diane Talbert: [inaudible 01:44:20]

Male: It's dead.

Diane Talbert: [inaudible 01:44:26]

Dave Cuttler: I'm sure that I'm not the only person in this position. I think it's a shame that all patients can't get the best drug for them at an affordable price.

Diane Talbert: I get [inaudible 01:44:53] family is not understanding all of what I was going through. Even though I [inaudible 01:45:02] my whole life to get [inaudible 01:45:04]

Dave Cuttler: When people feel good [inaudible 01:45:13] everybody.

Johnathan : That is the voice that cuts through it all. It is the patient voice. Somebody asked me once I was talking to a reporter. I've done- made many mistakes in my life. I remember he asks me- he says- I said, "Do you realize what happened today?" He said, "What did you mean?" I said, "A patient fought for their livelihood and their lives." He said, "Where?" He was writing down his number and I said, "Everywhere, everywhere, everyday what's happening is that patients are

setting a record. A record of courage. A record of commitment, and a record of compassion. Everyday they're setting that record."

I want to bring up everybody who you saw tonight. These are the true superstars of Voices of Value and making this enormous difference. Please everybody come tonight. Everybody up here, and I'm going to tell you why. Where I need to be is some [inaudible 01:46:45] honestly. I am so honored to be in this circle. I am not a patient or a survivor. I walk in the sacred steps of all these people. All these people. Please thank the amazing Jerry Mathers, Diane Talbert, my buddy Eric Boudreau [inaudible 01:47:12] come here. Most amazing nurse I ever met Karissa Tovar Dalmata. You love him Bob Goldberg [inaudible 01:47:34] Dani Yevsa. My legal eagle Stacey Worthy of Boston, Massachusetts.

I have been the loudest, but these, these are the true and real and lasting Voices of Value. For Patients Rising and patients everywhere from the Smith and Wollensky Castle in Boston's back bay my name is Johnathan Wilcox thank you and goodnight. One last point I want to make. One point I want to make is there was one entity not here that made this possible, that made this possible. The Global Healthy Living Foundation located in New York, but is everywhere. It's introduced us to so many patients that they are fighting for and making a difference for. If you have not heard of them you will have heard them now tonight and you see them in the patients who's lives they literally have changed and will change. They're extraordinary and they are amazing. When you see us here I hope that you will see them here as well. Please thank the Global Healthy Living Foundation.

How did we do?



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