Psoriatic Arthritis: Early Warning Signs, Diagnosis and Treatment
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Christopher Ritchlin, M.D.
Neil J. Korman, M.D., Ph.D.
Jarrod Taylor, Brenda Kong

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Introduction

Andrew Schorr:
Hello. Broadcasting live from Seattle, Washington, I’m Andrew Schorr, and the sun is shining today. It’s glaring on my computer screen. I’m celebrating that, but I’m also celebrating that we are doing this topic today, psoriatic arthritis, because it can be a lifelong condition when it develops for people, often psoriasis and then psoriatic arthritis. It can be very debilitating. What do we know about it?

Today you are going to hear from two leading experts, one rheumatologist, one dermatologist from two big university medical centers. We’ll hear about research. We’re also going to meet two people who have been living with these conditions, psoriasis and psoriatic arthritis, and hear how they’re doing, how they cope, the treatments they receive and how they inspire others, and that’s what we do always on Patient Power is connect you with leading, very credible experts and inspiring patients.

Often we have a partner who is helping spread the word and guide us as we go into new areas, and today we’d like to thank the National Psoriasis Foundation and them helping us put this program together and letting you know about it. Of course the replay will be posted on our website www.patientpower.info, on www.psoriasis.org, and also everything we do winds up on a new Microsoft Health search engine, www.healthvault.com. So it reaches many, many thousands of people.

Jarrod’s Story

Andrew Schorr:
Alright, let’s delve into our topic, psoriatic arthritis, and meet someone, my new best friend; we’ve been chatting just before the show. Jarrod Taylor is 32 years old. He is a middle school teacher, and I pay a lot of attention to that because I have a kid in middle school now. He’s in Woodland Hills, California. Kind of in the over the hill as they say from Hollywood and where UCLA is and all that in the San Fernando Valley, and Jarrod has been living with psoriasis starting at 12 years old, and then he developed psoriatic arthritis as well. Jarrod thank you so much for joining us.
Jarrod:
Listen, it’s my pleasure to be here today.

Andrew Schorr:
So Jarrod first of all I think we want to say that you are a very strong patient advocate, and although you have these conditions that we are going to hear about how they affect you, you don’t let it slow you down. What is this about break dancing?

Jarrod:
Well thank you for that. Yes I was diagnosed with psoriasis, a guttate psoriasis when I was 12, and I’m 32 now. So over the years the psoriatic arthritis has taken affect. Now in high school I enjoyed dancing, and break dancing of course was all the rage in the 1980s. Well now fast forward to 2008, I’m a school teacher, but I still work with some of the top dancers that you’ll see on recently the movie “Step Up 2” and “Dancing With the Stars,” and what we do is we do an anti-drug, anti-gang 45-minute assembly at high schools and middle schools where I’m up there dancing and seeing the show for hundreds of kids at a time, and it’s something I’m passionate about, just like speaking to people about psoriasis and psoriatic arthritis, and I wasn’t going to let this disease slow down the energy that I have inside you know.

Andrew Schorr:
Well that’s terrific. Now let’s just understand your situation though. You developed all kinds of lesions from the psoriasis. When did the psoriatic arthritis part show up, and how did it show up?

Jarrod:
Well if I may just, regarding the lesions, I remember I myself was a middle school student, and I was playing basketball one day. I went for a lay-up during the lunch hour, and as my shirt went up all of the myriad, the hundreds of guttate lesions were seen by the kids that were there, and I developed a nickname “Spot” and the kids would say, ‘See Spot study. See Spot eat lunch. See Spot play basketball,” and there was really, as you guys know, there is nothing you can do about it, I mean other than dot each lesion with creams and so forth, and so dealing with that and growing up with that I thought was bad enough, but then as I entered college, I went to UC Irvine, is when I really started to notice the swelling in the mornings of my fingers in my joints. I was taking martial arts then and still dancing, but I would just notice I would wake up and it felt like I had worked out with Hulk Hogan for six hours the night before, but really I wasn’t aware, but at the time it was the psoriatic arthritis developing. That’s really when it started to manifest.

Andrew Schorr:
Yes. Now we’ve been in the age of the biologic medicines that have been layered on top of the other medicines and other approaches that we’ve had for a while, and so you’ve been down that route. I know you started on one, and now you’ve switched to another. Have the biologics been helping you as well as other medicines?
Jarrod:
Listen, I am a perfect example of somebody who has run the gamut of medications for psoriasis. I started with coal tars, with every type of cream Westcort, Topicort, Peoples Court, basketball court, your court, my court, and I from Skin-Cap to PUVA, methotrexate, mean I literally you know tanning salons. I’ve run the gamut, and with my type of psoriasis I’m the rare case where guttate never went away, and so dealing with hundreds of lesions and psoriatic arthritis it just wasn’t, I couldn’t do the two-hour ritual anymore of dotting every lesion and then going out for work.

About six years ago when clinical trials were being initiated for Enbrel I jumped right on the bandwagon for that. Enbrel is a magic, magic concoction, absolutely wiped away my psoriasis. It really did, and within six weeks my swelling, the joint irritation, etc. was pretty much gone as well. After being on this wonder drug for, it was about a good five years, I just started to notice that for me personally, the efficacy as it related to my psoriasis, the psoriasis started to re-express on my elbows, my knees, and that’s when I switched to Humira, made by Abbott, and the Humira drug has taken me back to what I had initially with Enbrel.

I’d also like to say that this journey that I’ve taken is so personal, and I learned so much from it that about six years ago, before I started the Enbrel, I was really bad covered, and I was looking through the newspaper trying to find a support group to go to talk to people who are also afflicted like me you know, and I couldn’t find one. It looked like it was easier to be a drug addict to find support. I mean I wanted to go to a Narcotics Anonymous meeting and say, ‘Hey, I’m thinking about injecting Enbrel you guys. Can I talk to somebody?’ So since there wasn’t a group I started the L.A. support group which is now six years strong, and now I get help from the National Psoriasis Foundation, and I really just try to tell patients to really empower themselves, find the right doctor that doesn’t just treat you like a conveyor belt and slap lotions on you; that actually talks to you, gets to know you, and sees what the best treatment is for you, and yes, the Humira is the best treatment for me now. I’m totally, I’m dancing, I’m singing, my body is clear and it really has been a blessing.

Andrew Schorr:
Well all the best. Now I want to mention to people listening of course, your personal situation may not be what Jarrod’s is; both the exact situation or what drugs are right for you.

Jarrod:
Exactly.

Andrew Schorr:
So we’re going to talk about all that, but let’s go on and meet the docs, Jarrod. So first I want to start with Dr. Christopher Ritchlin. Dr. Ritchlin is an Associate Professor of Medicine and Director of Clinical Immunology of the Research Center, University of
Rochester Medical Center and he is an immunologist, rheumatologist, and we will meet Dr. Neil Korman in just a minute from University Hospitals in Cleveland who is a dermatologist, but Dr. Ritchlin we are talking about psoriatic arthritis. So maybe there is a greater understanding of psoriasis, and Jarrod was saying he got this nickname “Spot,” but when the joints start swelling that can happen too, not for everybody with psoriasis, and there can be an interval of many years usually following I understand. Help us understand what’s going on with the connection between psoriasis and then arthritis.

Dr. Ritchlin:
Sure Andrew I’d be happy to do that. Jarrod first of all you have a very compelling and inspiring story, and I thank you for relating that to us. Psoriatic arthritis occurs in about 25 percent of patients with psoriasis, and these numbers have varied over the years, but I think the consensus is coming forward that about a quarter of the patients with psoriasis will develop joint inflammation. In general that joint inflammation begins about 10 years after the onset of psoriasis, but there are certainly exceptions to that statement. Some patients may actually have the onset of arthritis before they develop skin disease, although they are in the minority. Some patients may actually have the onset of the skin and joint inflammation simultaneously, and there is even a very small number of people who will have all the features of psoriatic arthritis but no psoriasis, and generally those persons have a family history of psoriasis or psoriatic arthritis.

The mechanisms that link the skin and joint disease are still not well understood, but it clearly looks like it’s very different than rheumatoid arthritis, another common form of inflammatory joint disease. Rheumatoid arthritis patients tend to be a little bit older. They obviously don’t have psoriasis for the most part, and they tend to have a genetic background that’s quite different than patients with psoriasis.

I just wanted to say that when Jarrod developed psoriatic arthritis there was not much known about this disease, but over the last five to ten years there has been a lot more research that has been centered on psoriatic arthritis, and also we know that there is a variety of biologic agents, Jarrod mentioned two of them, Enbrel or etanercept and Humira or adalimumumab, which have really been dramatically effective for many patients with this disease.

**Treatment Options for Psoriasis and Psoriatic Arthritis**

**Andrew Schorr:**
Okay, well let’s bring in someone you know but on the dermatology side and that’s Dr. Neil Korman who is a Professor of Dermatology at University Hospitals of Cleveland and Case Western Reserve University. So Dr. Korman you have your psoriasis patients and as I said people may be more familiar with this, and then this other shoe drops. So tell us about the treatment for the psoriasis when you are treating, or maybe a rheumatologist however it works, is treating the psoriatic arthritis. Do you have two different approaches or can one work for both?
Dr. Korman:
Okay, that’s an important question Andrew, and thank you again Jarrod for sharing your story. I think I agree absolutely with Dr. Ritchlin. It’s patients like you who are willing to come out and talk about this that can make an enormous difference as I’m sure you’ve learned running this support group, and I think that Jarrod’s story really, it’s kind of a lesson really. As he said well he has been through everything, and certainly in places where patients are seen where they have a lot of experience, like both Dr. Ritchlin’s site and my site, we dermatologists and rheumatologists work very closely together, and we try very hard to talk to each other and to take the best care that we can of the patient, and we can do that when we can come up with therapies that work for both the skin and the joints, and there are many.

Not every therapy works both for the skin and the joints, and so the two biologic agents that Jarrod has been on have actually helped him in both cases I presume. At least that’s the way it sounded, that it has helped both his skin and his joints, and that’s kind of one of the exciting things about all this latest research that has been going on in the field is that the two diseases are linked. They are certainly are not the same disease by any means, but there are certainly many shared features between psoriasis and psoriatic arthritis, and probably it’s genetics that make the different for why maybe a quarter of people with psoriasis develop psoriatic arthritis, and three quarters are lucky enough to not develop psoriatic arthritis.

Andrew Schorr:
You know one of the questions that comes up immediately Dr. Korman among your psoriasis patients, they say ‘Well I’ve heard of this’ as I described it as “the other shoe that could drop” ‘in some percentage of the cases, can you tell me if this is going to happen to me?’

Dr. Korman:
Yes, that’s a fantastic question, and it’s the 64-billion dollar question. Millions of dollars are not worth anything, especially in this environment. So it is definitely the 64-billion dollar question, and lots and lots of work is going on to try to answer that question, but today we don’t have any answers whatsoever. Unfortunately we may have some clues, but we don’t have answers that we can tell patients, ‘Well here is the test that we’ll do that will give us the answer to whether or not you are going to be a lucky one who is never going to get arthritis or you are going to be an unlucky person who will get arthritis.’ So it’s a very important question, and some people have even wondered, ‘Well what about if we use a drug like Enbrel, etanercept, or a drug like Humira, adalimumab early when someone first gets bad skin disease?’ Could that prevent them from going on to develop a bad joint disease, bad arthritis? Certainly we don’t have any answers to questions like those, but they are very, very important questions.

Andrew Schorr:
Well we are all on a journey together. I think as there are newer approaches you all are both doing a lot of research, a lot of discussion going on and people are living with these
conditions. So Dr. Ritchlin, Jarrod brought up another point that maybe is happening now that we have had biologics around for a little while, and that is there was one biologic, Enbrel, which he described worked wonderfully for him for quite a while, but then he saw some things coming back, and he switched to another, and now he is getting benefit again. So how typical is that that you can’t just stay on one drug and expect that will work forever?

**Jarrod:**
I would like to clarify one thing. Is that all right?

**Andrew Schorr:**
Oh sure Jarrod. Go ahead.

**Jarrod:**
The Enbrel at the end of the five years, my joint pain and stiffness was still almost 100-percent better. It was just really the skin that was re-manifesting on those parts of my body, and at this point it had been five years of living in clearness, and I got a little spoiled actually having relatively normal skin, and I wanted to get that again, but in terms of how I felt with the joints and stiffness, that was still A-okay even at the end of my Enbrel.

**Andrew Schorr:**
Great, thank you for that. Yes it would be great if we had a one size fits all, and we were just talking about that. So Dr. Ritchlin, help us understand. He was getting the benefit in both conditions and then that started to wane a little bit. So do people have to switch or do they need two different approaches?

**Dr. Ritchlin:**
So Jarrod’s experience we see not infrequently. I think it’s important to point out that the biologic agents like have been mentioned so far, and infliximab also called Remicade were really first developed in rheumatoid arthritis, and the response to these drugs in rheumatoid arthritis in general, from the perspective of the joint pain, is not as robust as it is in psoriatic arthritis. So in general patients in psoriatic arthritis that are treated with the anti-TNF agents, any one of the three we’ve already heard about, tend to do extremely well and better than patients with rheumatoid arthritis.

Now having said that, there are some patients who will break through these medications after having sustained a very dramatic response, although I must say in our experience, and we’ve followed over 300 patients, that’s unusual. When we do see a breakthrough in patients with psoriatic arthritis, as in Jarrod’s case, it’s more commonly with the skin becoming active than it is with the joints, and the mechanisms that as why you are seeing control in the joints and not in the skin after a period of time is still one that’s open to speculation.
Dr. Korman may have some other thoughts on that, but in general when we do see a patient who has a flare on an anti-TNF agent, especially in the skin, what we do is we work with our dermatologists; I know they do the same thing in Cleveland, and we work with them to say, ‘Do we need to switch to another anti-TNF agent, or can we use additional modalities with the current TNF agent method, methotrexate, cyclosporin, light therapy, topicals?’ And sometimes as in the case with Jarrod, his skin disease was so severe that some of these other options which hadn’t worked before were not tried because of their inefficacy, and one needs to switch to an alternative anti-TNF, which in many cases can be as effective, but I’m sure Dr. Korman will have more thoughts on the skin part of this as well.

Andrew Schorr:
Yes, go ahead Dr. Korman. Weigh in on that.

Dr. Korman:
So I absolutely agree with everything that Dr. Ritchlin said, and yes it’s a problem that we have. Often you are going along and a patient is being treated, and everything is going along well, and sometimes you will lose the effect of the medication, and skin is usually where the effect is lost. So often we can consider augmenting, adding something else. So we can add anything from creams and ointments, which patients don’t like at all and tell you they won’t work, but often they will work if the patient is willing to use them, and that’s sometimes a big “if” because they have been sufficiently frustrated and annoyed about this, as Jarrod said earlier, the two hours to put stuff on his skin. So somebody like him with bad guttate disease it is obviously a less practical approach to think about creams and ointments, but sometimes people will have a bigger area where it doesn’t take two hours, and maybe it takes a half an hour.

Still it can be an enormous amount of time and burden. So I don’t mean to minimize it, but topicals would be an approach. Adding ultraviolet light would be an approach. Adding even other oral medications, some of the ones that Jarrod talked about, and we have from the world of rheumatology there is a great deal of experience combining a drug like methotrexate that he took before with Enbrel, and again even if the methotrexate didn’t work alone very well in the past, often it will work a whole lot nicer when it is combined with an agent like Enbrel.

So those are all the options and opportunities that we can consider before we think about switching an agent, but my experience has been that a lot of times when somebody starts to lose effect from an agent you often can’t regain it back, and so it is sometimes absolutely the right thing to do to say, ‘Well we can’t continue with this medicine anymore.’ In Jarrod’s case it was being used to treat both his skin and his joints, and his joints continued to be fine, but his skin was becoming very severe. So it sounds like it was perfectly appropriate to switch him from Enbrel to Humira, and he’s had an excellent result so far. So that’s good news.
Choosing the Right Specialist for Your Condition

Andrew Schorr:
We’re going to take just a brief a break in a couple of minutes, and then after the break we’re going to be joined by someone else who has been living with psoriatic arthritis, and it greatly depressed her. As life went on it became really tough. Brenda Kong will be joining us, and Jarrod I want you to stay with us.

I want to ask a quick question of Dr. Ritchlin. Dr. Ritchlin when I listen to these discussions I am always impressed by the art of medicine. Not just the science. So it would seem to me if somebody with psoriasis is starting to get some aches and pains, well it could be other things, that just briefly sir it would seem like you do want to have a consultation with somebody who is knowledgeable in this area, and maybe raise the question of do you consult with a rheumatologist or ask your dermatologist about do you need such a consultation. What do you think?

Dr. Ritchlin:
I think either of those is an action that should be taken. I think that I know from experience and working with people like Dr. Korman and other dermatologists around the country that there is a marked increase in awareness of the musculoskeletal joint complications of psoriasis, and dermatologists are very quick to refer to a rheumatologist if one of their psoriasis patients is experiencing new onset of joint problems.

What we often see are patients who have psoriasis who may not be seen by a dermatologist and are being cared for by their primary care physician who go on then to develop joint manifestations. So I think it’s very important, and we’ve been working on this for some time now, to get the word out to not only to primary care physicians, orthopedic surgeons, podiatrists to let them know that when they do see patients with psoriasis they need to be followed by a dermatologist, and if they are having joint pains that rheumatology should be involved as well.

Andrew Schorr:
Okay. Great answer. Now we are going to take just a short break. We are talking about psoriatic arthritis with help from the National Psoriasis Foundation, some great doctors and great patients. We will be right back.

Andrew Schorr here with Patient Power. Welcome back to our live webcast. We are talking about psoriatic arthritis. Remember our friends at the National Psoriasis Foundation are there to help you all the time, and that is www.psoriasis.org, and they have a phone number, and people standing by to help, 1-800-723-9166 for help on psoriasis and psoriatic arthritis, and thanks to them for helping today.

Just a quick mention of some programs we’ve got coming up. I will be going to the American Society of Hematology meeting, 30,000 researchers and doctors in San Francisco this weekend, and on Monday we’ll do a live webcast with my doctor, Michael
Brenda’s Story

Andrew Schorr:
Let’s go back to psoriatic arthritis, and we are joined now by someone else who has been dealing with this now for a few years, and that’s Brenda Kong who is actually a nanny in Oakland, California. Brenda I understand, like we were hearing earlier in the program, first you developed psoriasis at age 13, and you are 28 now, and then at 21 came the joint pain. So it followed by a number of years. Did you know to expect that arthritis, psoriatic arthritis, might follow the psoriasis?

Brenda:
No. Absolutely not. I actually had never heard of psoriatic arthritis until maybe a year or so after I started having symptoms. So it was not something that I’ve ever seen, but when I was growing up with the psoriasis it was not something that I even paid attention to. I saw it as spots that I took care of with a cream or an ointment and a dermatology appointment every so often. So it wasn’t something that was a part of my life until I was about 20 years old when I got extremely flared and covered, and my joints started to go that I actually started to really pay attention to it.

Andrew Schorr:
So you had a flare of your skin condition and then the joint pain along with it. Is that what happened?

Brenda:
Yes, it was kind of a progressive thing. I started to get more skin involvement at about 20 or so, and I never had much during my teenage years. It had always been isolated spots, but this time it started being more full body plaque, and then I started to develop the psoriatic arthritis, and from about 21 to 23 or so at one point I was about 98-percent covered and I couldn’t walk. My joints, it progressed so rapidly it got to a point where one toe started to hurt, then it was a few toes, then an ankle, then my wrists, my elbow, my neck, my hips. It just progressed rapidly on me.

Andrew Schorr:
Brenda we should mention, I know you have shared this and speak out about it, when you were so covered life didn’t seem like living did it?
Brenda:
No it did not, and for me at that time I was very young, and I was very active socially. I was in school, and I was working, and I was doing the entire Bay Area club and party scene, and you know doing that your self image is so completely just shot down because you see all these other women, and their skin is beautiful, and it was not a great image for me, and I got to this point where I didn’t want to deal with it; I didn’t understand what was happening with me. I didn’t know when I’d be better or if I would be better. I didn’t know or understand.

You know at this point in my life I kind of felt that I knew a lot, you know, and I thought I knew enough where I didn’t need to ask anyone else. So that’s a good way of putting it, and I was at my lowest point and I did try, and it didn’t work obviously.

Andrew Schorr:
Well we are all thankful for that Brenda. Well here’s the point of this program is there is information. So for people listening if you get to that deep depression, and hopefully you don’t though, there are things to talk about with qualified doctors, and we have two of them with us now, Dr. Christopher Ritchlin who is a rheumatologist and a research leader at the University of Rochester Medical Center in upstate New York, and then Dr. Neil Korman who is a professor of dermatology at University Hospitals of Cleveland and Case Western Reserve University.

Let’s ask Dr. Korman a question I’ve been wondering about as we listen to your story Brenda. Dr. Korman would a dermatologist or a patient see a change in the psoriasis if we are getting to the point where psoriatic arthritis is beginning to be triggered? Will it look any different?

Dr. Korman:
No, typically not. The patient will feel different. They’ll say, ‘You know I don’t feel right. I’m feeling achy, and I’m feeling tired. I can’t do much. I can walk. It hurts when I walk. I’ve got these swollen joints. My Achilles tendon is swollen. My elbow is swollen,’ but typically the skin lesions themselves don’t look any different, and so sometimes it’s a tough diagnosis to make, and as terrible as your story is Brenda, at let’s see, so that’s eight years ago, or it’s 15 or 16 years ago when you were first diagnosed, then at that point the awareness in the dermatologic community was really not there at all. So it doesn’t surprise me at all that nobody said to you well you had this skin disease, but you might get a problem with your joints at some point.

Now I’m happy to report that many more of us dermatologists are aware of this, and we’re all working very hard. Doctors like Dr. Ritchlin and I are working very hard to get the message out and the National Psoriasis Foundation is working very hard to get the message out to educate patients and other physicians in other fields as well that psoriasis patients can develop psoriatic arthritis, and it’s very important to catch it early. If you catch it early you can treat it much more effectively, and patients don’t have to suffer as much.
Signs and Symptoms of Psoriatic Arthritis

Andrew Schorr:
Let’s ask Dr. Ritchlin more about that. First of all Brenda mentioned starting to get, you know, her toes hurt and everything. How does it show up? Does it vary by people? Also comment on this sort of early intervention, the benefits of that.

Dr. Ritchlin:
Sure. First of all, Brenda thank you for sharing your story with us. It sounds like obviously this was very difficult, but that you have moved beyond that. I’m very pleased hear that you are doing better and doing well.

Psoriatic arthritis is very unusual in that it can come on in many different ways, and there are basically four different ways that one can first see early symptoms of psoriatic arthritis. The first, as Brenda has already mentioned, is a swelling of a digit, that could be either a toe or a finger, and it often looks like a little sausage digit. It’s very painful and sometimes can be misdiagnosed as an infection in the nail called a paronychia, but it’s really an inflammation in the tendons. It can be very painful, and often in some patients it’s the first symptom and sign of psoriatic arthritis.

A more common presentation is sort of the gradual onset of stiffness and pain usually in several joints, not necessarily symmetrically on both sides of the body as we see in rheumatoid arthritis, and the joints that tend to be involved are the small joints in the hands and the feet, but also larger joints like the knees, the ankles and the shoulders.

Another presentation of psoriatic arthritis seen in up to a third of patients is involvement of the spine, and that presents typically as morning low back pain. So a person gets up in the morning. They are stiff. They’re back is hurting, and as they move around as the day progresses the pain improves. So oftentimes these people are young, and they deal with this by exercising in the morning; yoga, running, any kind of activity tends to make that pain better, and they often don’t come to medical attention for some time.

Then there is another group that gets what we call enthesitis. Think of tennis elbow or golfer’s elbow where you have pain over the outer aspect. There is no obvious swelling or redness, but it is extremely painful. Also it can involve the Achilles tendon or the bottom of the feet, the plantar fascia. These patients frequently come to medical attention late because they are misdiagnosed. ‘Oh, it’s just a tendonitis; it’ll get better,’ or ‘Oh you are just suffering from growing pains,’ but this can be a very debilitating feature of psoriatic arthritis, and it can lead to functional problems.

So it’s important to make a diagnosis early as Dr. Korman mentioned because it’s very evident that early intervention can not only improve function, but can also relieve pain and lead to help prevent or slow down any subsequent destruction or damage to the joints and surrounding tissues.
Connecting with Others for Support

Andrew Schorr:
Right, and I’ve done a number of programs earlier on rheumatoid arthritis, and I’ve learned so much. Joint destruction is sort of a one-way trip and that you may need an artificial joint; all sorts of surgery later, and you don’t want to get there if you can. So I clearly understand that.

As I mentioned the first fellow that joined us, Jarrod Taylor, is a schoolteacher. He’s got the substitute working in his classroom at Hale Middle School so he could be with us, and I want to just mention, we talked about the National Psoriasis Foundation, and Jarrod has gotten very involved and also has his support group in Los Angeles. Jarrod, people are not alone, and certainly you have worked hard on that in L.A. What have you got going there to bring people together?

Jarrod:
Listen, I had such a, similar to Brenda, such a terrible experience through middle school and high school being covered in the multiple psoriasis lesions, getting the terrible nickname of “Spot,” trying to just live my life and go to class, and ‘Hey, see Spot study. See Spot read a book’ so bad that the final year I made friends with my ceramics teacher and just took shelter every lunch in there, and he and I would watch “Twilight Zone,” the black and white one. So I’ve memorized every episode and was able to escape the final year of insults, but after going through that experience in high school as well, college I knew that I had something inside me to create a space, a place for people to come together and talk about it because similar to Brenda I was on the brink of destruction. Looking in the mirror one day covered head to toe like a leopard, like I had leprosy, like my body was out of control. I couldn’t live like that anymore.

So what I had going on here, about six years ago I founded the first ever support group for psoriasis. Of course it’s a free once every two months meeting that we have in central Los Angeles. It’s open to anyone; people with psoriasis, psoriatic arthritis, family members. We have physicians come. Dr. Yamaguchi, Dr. Weinstein has come, Dr. Lo. Tons of doctors come through on their own time, which is like the doctors we have here on this program. Doctors that take that extra step that really do care and that really are in the know.

One of the big things I try to get across to my friends who come to these meetings is it is really up to the patient to be empowered, and like these fine doctors mentioned earlier, there is a lot of education going on about the new bastion of medications, the new interleukin drugs, the new anti-TNF stuff. A lot of doctors may not have access to it. So if you are hearing my voice and you are suffering like Brenda and I are suffering, and your doctor just doesn’t seem to be cutting it or he seems to be treating you like the conveyor belt or throwing topicals at you from the Fred Flintstone age, please take it upon yourself to find a doctor like these two doctors on this radio program who are empowered, who are
knowledgeable about what’s out there. That’s really what I try to bring to the consciousness of people with psoriasis. We can do more than these old Fred Flintstone approaches to what poor Brenda and I have been suffering from.

**Research In New Treatments and Possible Cardiovascular Link**

**Andrew Schorr:**
Thank you Jarrod. We’re going to let you go, and go back to school. I’ve got a sixth grader, and there are kids waiting to hear about computer science and English from you. So thank you for what you do.

So this is such an important point. He was sort of joking about it, sort of, the Fred Flintstone age of medicine for psoriasis and maybe even not knowing that there was psoriatic arthritis, and it sounds like with you leading experts that really there is a lot of medical education going on but that the patient can really insist on getting the latest care. So that leads me just to a couple of questions about research, and Dr. Ritchlin I’ll ask you first.

So we have the medicines we have now, layered on top of ones that have been effective for different people along their journey. Where are we headed next Dr. Ritchlin?

**Dr. Ritchlin:**
Well I think that it’s important to understand that the advances that we’ve made to date really stem from very careful scientific work in both psoriasis and in joint disease, and also from a bedside where we learn that TNF inhibition is very effective for both skin and joint disease.

I think that one of the exciting areas now is that there is a whole new pathway in immunology which has been really revealed since 2006, and this is called interleukin-17, and IL-23, which is a whole different set of cytokines that seem to be integrally involved in psoriasis. I know we are going to be seeing agents that are directly to that pathway. They are very effective in the treatment of psoriasis, although their role in the treatment of psoriatic arthritis has yet to be fully defined.

The other area of research we’re involved in, and Dr. Korman can mention his area as well, is we are very interested in identifying factors in psoriasis patients that put them at risk for arthritis. So these include imaging studies and cellular markers that we are hard at work on.

The last thing I want to say in regards to this is, it’s important to remember that the state of the art medicine for the treatment of psoriasis and psoriatic arthritis doesn’t necessarily mean biologic agents. There is still a role for therapy with light therapy and topical agents and methotrexate in certain patients. So I think what’s important is we now have a whole array of compounds and agents available to help our patients, and that’s really exciting.
We also have a lot more knowledge about how to use them among rheumatologists and dermatologists.

**Andrew Schorr:**
Right. No I agree with that, and you know I want to make that point to people. I was in a clinical trial, and it ended up working and working for me and many people to follow, but the latest and greatest or the newest under study may be right for you, may not, may be effective, may not. It’s your personal situation, and that’s why my mission of Patient Power is to urge you, just as Jarrod was saying, connect with a knowledgeable provider, maybe it’s going to be more than one, to help you sort this out, and then as you are on a journey with what will then become a lifelong condition, you know see whether things change for you, whether the available therapies change. That’s an ongoing dialog with someone that you have high regard for. So you need to find someone. Certainly the National Psoriasis Foundation can connect you with providers who are knowledgeable in that way.

**Dr. Korman:**
What about research in your area? Where are things headed? What are you excited about?

**Dr. Korman:**
Well I think that there are a lot of very important areas in dermatology and psoriasis, and the largest area that we are most focused on is the risk of developing other comorbidities. So we haven’t had the chance to talk about this at all, but there is a growing body of literature that actually probably came first from the rheumatology world that demonstrates that people with inflammatory diseases, of which psoriasis and psoriatic arthritis fit in to this category very nicely, that patients with these diseases may have an increased risk of cardiovascular disease, and there is a newer understanding that cardiovascular disease; and by that I mean atherosclerosis, I mean patients who get a heart attack or get a stroke or get difficulty walking, the peripheral vascular disease; all of these seem to be increased in patients who have inflammatory diseases and psoriasis and psoriatic arthritis are those diseases.

So we are working very hard to establish in a rigorous fashion whether or not psoriasis patients have an increased risk of cardiovascular disease, and perhaps even more importantly then establish it because I think that there is a fair amount that suggests it’s already true, but more interestingly in fact would be to then go back and take these patients who have known psoriasis and see whether or not if we treat them aggressively with whatever agents are available to treat them, will we in fact influence their risk for cardiovascular disease, and so that I think is an absolutely critical arena, and it’s critical because it is very important, and it would demonstrate that for the patients who just have skin disease that it’s not “just” a skin disease and that oh it’s not important. It’s just a skin disease. It’s just a rash. Who cares? Don’t worry about it.

Not that we want that, you know, not that we want to tell our patients, ‘Oh well, good news. You have a more serious disease,’ but if indeed it is the case then we certainly want
to be in a position so that we can make inroads and improve people’s health, and one of the issues that hasn’t really been addressed today is that some of the newer therapies are quite expensive, and sometimes patients get blocked by their insurance companies from being allowed to use these therapies. I think that if our data were to show that well in fact psoriasis patients do have an increased risk of heart disease and that if we treat their skin aggressively we may decrease their risk of heart disease that would be an absolutely critical area for improving health care coverage for these therapies.

Andrew Schorr:
Good point, and as I mentioned, I was in a clinical trial. Now our guests today Dr. Ritchlin from the University of Rochester, Dr. Korman from University Hospitals in Case Western Reserve in Cleveland, they have very active clinical trials going on. I urge people with a chronic condition like this to consider being in a clinical trial. So for instance if there’s research looking at cardiovascular inflammation, is it connected, can these medicines help, and then that may give you access to therapies or certainly help tell the story for the people who may ultimately hopefully write checks for the therapies you need. Consider participating.

Okay, we have so much to cover I wish we had more time. I want to mention though that this is an ongoing dialog. I hope we do more on Patient Power. Certainly take a look at the National Psoriasis Foundation and everything they have to offer. Their phone number is 1-800-723-9166 and www.psoriasis.org.

I want to go back to Brenda just for a minute. Brenda you’ve been listening, and you’ve been on a journey, and you don’t know where it’s headed next. Thank goodness you are doing better. What would you say to somebody listening so that they get care and have hope?

Brenda:
Absolutely. When I was at my lowest point I actually did finally go out, and I started learning, and I started researching, and I finally went to see a rheumatologist who put me on Enbrel, and I was able to walk again, and it was incredible, and you know I don’t know if it’s right to say this, but this is actually a very exciting time to have psoriasis and psoriatic arthritis because there is so much information out there with the Internet and the incredible foundation that we do have. There is so much information, and I actually do run a support group. We have a support group here in San Francisco, and we just celebrated our four-year anniversary in October, and I never would have started it if I did not decide to look into this and become a powerful patient for myself and realize that I can not look to doctors to only be the ones to take care of me; that I have to look at myself as well to take care of me, and what I always tell people is if you are interested in any kind of treatment, whether it be a biologic, light treatment or oral, to please write down as many questions as you possibly can, and research these drugs first, and then go into your doctor with a list of questions, and if that doctor cannot sit there an answer those questions completely for you, then that might not be the doctor for you.
Taking care of yourself is having a complete entourage of incredible doctors, of support whether it be from the support group or your friends and family, and it’s opening up and talking to them. Throughout my entire years of being a leader and going to Washington D.C. to actually advocate for our psoriasis bill, and we actually do have the very first psoriasis bill in government now which is completely exciting, is to realize that your life is a roller coaster. There are ups and downs, and when you are at that low point that there is a high coming, and that high is going to be beautiful.

Andrew Schorr:
Wow. Brenda you are so articulate. We wish you all the best. Dr. Korman, is there a 30-second comment you’d care to make?

Dr. Korman:
Well I think the main thing is that patients listening should realize there is a lot of hope and that I would strongly encourage them to seek out care, and sometimes seeking out care means getting in the car or getting on an airplane and going somewhere else, and I think that that’s very reasonable and very appropriate. You just shouldn’t sit back and say, ‘Well my doctor says this. You need to, to --- I think that’s the name of the program isn’t it? Patient Power. So I’m going to support the title of your program and encourage all the patients to be empowered to take care of themselves.

Andrew Schorr:
Thank you. That’s Dr. Neil Korman at University Hospitals of Cleveland and Case Western Reserve University. Dr. Ritchlin I’ve got about 30 seconds for your summing up comment.

Dr. Ritchlin:
Yes, so I can’t say it any better than Brenda did, but I think it’s important to point out that there are centers around the United States who are very interested in psoriasis and psoriatic arthritis and related illnesses. There is one in Cleveland where Dr. Korman is at Case Western, Rochester, Oregon and Toronto up in Canada, and these are centers where doctors have a specific interest in psoriasis from rheumatology, dermatology, cardiology, endocrinology, nutrition, psychiatry, psychology are interested in helping patients with psoriasis deal with some of the issues that they may face, and these are other centers that patients may think about contacting.

Andrew Schorr:
Wow. Okay thank you. That was Dr. Christopher Ritchlin who is at the University of Rochester Medical Center. Thank you, thank you so much for participating, and the National Psoriasis Foundation is a wonderful resource for people afflicted by psoriatic arthritis and psoriasis. So be sure to go to www.psoriasis.org. Tell others about Patient Power. We’ll have the replay up as quick as we can later today at www.patientpower.info. We’ve got ongoing programs, and we always welcome your suggestions at www.questions@patientpower.info. This is our mission to help you get the best care and have a full life.
I’m Andrew Schorr. Remember knowledge can be the best medicine of all. Have a great day.

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