Turning Your Patient Perspective Into A Paid Opportunity Transcript

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Introduction to Kathy Regan Young

Welcome to another episode of the Ms.. Autoimmune Doctor Talks summit. Now, my next guest, Kathy Regan Young, she's a prominent patient advocate and a founder of two innovative organizations firms.

Now, that's a few Ms.. Now, it does stand for what you think. And patients getting paycom. She's become a leading voice in the patient advocacy space.

Driven by your own personal experience with multiple sclerosis. Katie's journey began as a patient advocate when she was diagnosed with multiple sclerosis in 2008.

She quickly realized the impact that chronic illness can have on a person's life, and became determined to make a difference. In 2010, she founded the Fumes now.com website dedicated to providing resources and support for people with M. S..

2015 she launched the F ums Podcast Show, a companion to her website, where she interviews and experts inspirational Ms. patients to bring information, inspiration, motivation for living your best life.

In 2021, Kathy launched Patients Getting Paid, a membership community that empowers patients to find, create, find a create work that accommodates their health and generates income.

She calls them chronic partners and is, proud of the success she's seeing inside the membership through a group coaching, accountability, weekly conditions, specific gig opportunities, and co-working within the community.

Again, welcome. Kathy. We're super glad to have you. Okay. Kathy, I thought we should start with, your, diagnosis and your journey to discovering that you have multiple sclerosis.

Sure. Well, that was, back in 2008, and I woke up one day, and nothing looks right. I couldn't have explained to you what was wrong with my eyesight, but I knew something.

MS Diagnosis and Early Vision Symptoms

And eventually what we found was after going to a couple of different doctors, was, an ophthalmologist told me I had six nerve palsy and thankfully that ophthalmologist said that is not an answer.

That's a symptom of something else. So we need to track this down. I'm going to get you in with a neurologist. You're going to get an MRI. Excuse me. You're going to get, a lot of bloodwork, a lot of tests and a lumbar puncture.

And about a month later, I had the answer, and it was Ms.. So the sixth nerve palsy, for our listeners, can you describe that? Sure, sure. It started out, as I said, I remember looking out the window and thinking that, like, everything looks off.

I kind of felt like I had the flu. My eyes hurt when I moved them, and I couldn't describe what it was that looked off, but it looked off. And in the course of about 2 or 3 days, my vision had doubled.

And then you sound vision. Yep. Yeah, yeah. And the fatigue too. But I had two little ones, so I kept talking everything up to. Well, I'm just an exhausted mom. Sure, sure.

You know, and, again, for the listeners, I want you to know, I believe about 25% of people with M. S. start with a visual, symptom of some type. If it's straight optic neuritis, our visual acuity goes down.

We have difficulty reading, and so the difficulty with clarity, if one of the, cranial nerves that control movements of the eyeballs, then we have difficulty coordinating the movement.

And just as Kathy described, the world doesn't quite look right because we're not able to get our eyeballs to move together in merge the two visual fields that we see from the right eye and the left eye.

And so, again, the most common is optic neuritis, where we lose acuity. We can't quite read. That's usually why we're going in, but sometimes it's, what Kathy describes.

We can tell that our vision has changed. It's hard for us to know exactly how it's changed. And then, double vision, is the third most common that you have.

Double vision. And hopefully you also have a, on the top of the game. Eye doctor says, well, we need to look into this further. Yeah. Thank you for that. Opthamologist. Yeah.

And so you got, in 2008, you were told, like, okay, this is multiple sclerosis. Then what happened? Well, I, I've heard this story over and over from other.

So I know it's not just mine. The neurologist who, diagnosed me pushed three huge binders across the desk to me and said, here are your choices of medications and go read these and call me back within the next two weeks.

I'd like to get you on something, but you tell me which one you want to start on. Which what? So it's so funny to me. I just did not make a recommendation.

I just said, read this. This incredibly medically dense information. When you're in the middle of this flare and scared to death, and you come back and tell me what you want to get on.

And, had we able to read, how was your vision at that point? I had to cover one eye to be able to see, to read. Okay. So, struggling, probably struggling. Yes.

And the fatigue was horrible. So I laying there covering one eye, trying to read this. And what I later learned was fog. Fog was certainly present.

Initial Treatment Challenges and Medication Changes

And I'm trying to decipher all of this and take in the fact that now I have this diagnosis that I really don't understand, and two little kids looking at me like, when are you going to make dinner?

And were you a single parent at that time, or did you have no, no. So you had you had a spouse who was? I did hopefully being very helpful and supportive.

That's helpful. And he could be, but he works a lot. So he's, you know, wasn't around a lot. Okay, so you read through this, and after two weeks, did you make a decision and you started something I did?

Yeah. Do you want me to say what it is I just started? Sure. Yeah, I chose to around, which was every third day I think that I gave myself a shot. And, you know, I started so quickly after learning my diagnosis that I really didn't know anything about Ms..

Or much about this drug. And so and as it turns out, I stayed on that drug for five years, fully convinced that if I came off of it, I think I would, you know, I don't know what I thought, but I was very scared to come off of it.

And not knowing the difference between Ms. and what turned out to be horrible side effects of the drug, I assumed this was Ms. and it was really bad for five years.

But as I said subsequently, I learned that was once I came off that drug. I felt much better, but so I was just like, oh

God. So I felt so it was every, I believe, third day that I gave myself an injection that night and the next day and potentially the day after.

Certainly intuitive bit, I felt like I had the flu. I was I could be feverish, I had body aches. Of course there's this fatigue. But also in the middle of the night after I gave myself an injection, oftentimes I would wake my husband because I was shaking so hard and he would have to, like, stretch me out because I was just.

I was in a ball. It was just. Yeah. Not good. So normal. You go off the beater siren, you go on to another medication. Not initially. Initially, I was just so over everything.

I just decided I'm going to see what this is like without anything, which I did for four years. And I felt so good right up until I didn't. When I had a huge flare, of which I still have, my right hand is still numb since that time. So, excuse me, just after that, once I had this big flare, then I went back on, and I went on to tech for there by that time, there were oral medications.

Yeah. Which I also had a lot of problems with the injection sites. I just had lumps all over me. I remember my my kids were little, and they would hug me and I'd go, oh, don't don't touch me.

Spot. My spot hurts. Yeah. And so the tech era went well. It did. The first six weeks were pretty rough. A lot of stomach issues. But once I got over that, it was like turning on or off a light immediately.

I was fine, and I did really well with that for a number of years until my insurance company took it off. Formulary. And then, you and I, well, I went to Germany, which is very close, obviously to tech for there.

And I did well on that. Until last year, I guess it was. And, I had gone in for just a regular. I was doing so well, my, my neurologist, even said to me, you know, we can talk.

You're getting older and and you're doing so well. You're my most stable patient. We can start talking about maybe going off of DMT. And how old are you at that time? 59.

Okay. And he said that sent me for my annual MRI and then called me at home at 7:00 at night, which is never a good sign. And he said, I can't even believe this, but you have a new lesion and you have two old lesions that have grown significantly since your last MRI.

So, and this was completely subclinical at the time, I felt fine, but it wasn't too long after that I started really feeling it. And so then let me stop for a moment.

For the listeners, I think this illustrates a really important point why continued surveillance is worthwhile. Because then you can detect disease activity that's not yet overtly symptomatic.

And for all the listeners, I want you to know that I still, at age 69, go in for surveillance MRI. So, back to you, Cathy. Cathy. Yes. So then, post that revelation, I went on to, Brian B.

So that's every six months, approximately, I get a an infusion and so far, so good. Okay. So, you're doing well. And how old are you now, my friend? I'm 60. 60.

All right. You look great. You're feeling great. Doing well. Now, I know that you've also created a business. Can we talk a little bit about your decision to make a business and what this business is?

Sure. So, when I was diagnosed, my doctor, I was a stay at home mom, and my doctor said to me, I'm so glad that you don't work. Currently stuck in my car when he said that.

I'm so glad you don't work because stress is the very worst thing for Ms. and so you should never go back to work. You should really take it easy. In fact, I remember asking him, are there any any special diets I should be following?

Or and I said, sizing 2008. Okay. And he said no. Nope. Nothing. Nothing to change. In your diet. And you really should not be exercising. You really should be just taking it easy.

So that told me a couple things, because I immediately in my gut knew that wasn't right for anything.

Building a Work-From-Home Career

And he clearly had never stayed home with kids because that is the most stressful job I ever had. And I also from him saying, don't ever go back to work.

What I heard was go back to work as soon as possible, which I did when my kids work full time in school. I went back to work for a couple of years, but I will say I did have a lot of flares.

Then. From that time. So I did have an awful lot of stress from that job. And so I left that job and came home and, and immediately felt much better. But as I always say, my bills quit coming.

But I mean, my checks quit coming, but my bills didn't, so I needed to figure something out. What can I do from home? And this was pre-COVID. So, you know, post-Covid companies are more open to allowing you to work remotely.

That wasn't a thing back then. So I knew I needed to create something for myself. And I had started, a website in 2010 called FMS or FMS now.com. And then in 2015 I started a podcast.

So, I had what I knew was an asset. I just did not. I knew people monetize those things blogs, but I didn't know how to do it. So I set about to figure that out and I did.

And realized one day working in the garden, by the way, which is like my favorite exercise that I was making more working for myself than I had been working for someone else.

And I didn't have to ask for time off to go to the doctor, or if I was too tired to work, I had my own schedule, so it all made sense for me. And then I also realized I had an obligation to help others do the same thing with chronic illness.

So then I started something called Patients getting Paid to help others learn how to do it too, because it's so hang on. So patients getting paid. Yeah.

And that was the the name of the company. Yes. Yeah. Well the company's PR plus and under that is FMS and patients getting paid and patients getting paid as a membership community to help people with chronic illness, to find ways to make money from home to just take care of themselves.

Accommodate their health, but still generate an income. Oh, that sounds, pretty interesting. So people come to the membership site and it's business coaching or, we have a lot of every month I do, an interview.

I find someone, an expert in, let's say, one of them was voiceover work. So I look for businesses that fit into the criteria of extreme flexibility. Hopefully that you can do from home and, you know, yet generate an income.

So, for instance, I found someone who had, started their voiceover work and been very successful. And so I interview them. So we do trainings, we do, co-working.

I do twice a month coaching sessions and, and there's a community in there. So they help each other. So voiceover work, for the listeners, they probably don't know what voiceover work is. Sure.

So, as you watch commercials, oftentimes you'll see, you know, you're looking at something and you're not seeing a person, but someone's speaking. There's that that's voiceover work.

There's, narration of audiobooks. Somebody's got to read that. Things like that. Okay. So that's one one of the possibilities. Are there other, possibilities that you were talking about?

Yes. What I've found has been one of the most popular is, is writing and whether that be for condition specific. So I also have, every week I post condition specific, gig opportunities.

And so there's a lot of companies who are looking to hire patients to learn from them. Whether it's they want to show you their marketing materials for your specific condition, just to run it past you to see if it makes sense.

It speaks in your conditions, language, something like that. Or and those are called advisory boards or sometimes, they're looking for ambassadors. Condition specific, you know, patients to come and speak on, on their condition, whether it be to doctors or to, other patients, there's a lot of different opportunities.

And so we post about that as well. But the, the, the writing seems to be one of the most interesting to people. That and patient advocacy itself, which, you know, there are since I started all this, there are all these opportunities out there.

There's everyday health, there's health line rvo health. Excuse me. And they're all looking for content all the time. So writing articles, POF articles in particular, which stands for Point of View.

Yeah, they need a lot of that. And that's something we can share. And so the people who are beginning to write, are these folks who have gone to college, there are English majors now in the majors. Nope. Not at all.

It can literally be anyone when it's point of view in particular, because that is really sharing your experience and what you've been through. And how it felt to you.

And there's a lot of these big health information companies online that are in need of, you know, constantly feed the content monster. So, okay. And so these point of view articles, you get, connected with a company looking for a point of view article.

Right. And many of our listeners will be, of course, multiple sclerosis or perhaps one of the other new immune conditions that sort of look like M. S..

And so you get paid for one gig or you likely get a relationship with, one of these content. It it really depends. It's certainly going to just start out with one gig as you build your portfolio and we talk a lot about that as well. In.

But for instance, I started with Healthline seven years ago. I helped them build their their EMS app. And so this is another sort of gig that I, I do these kinds of things pop up here and there.

So I do a live chat. I'm the guide in that app and it's all about EMS. And so I'm in there helping people and conducting these live chat. Well, because I was working with that company already.

They, when they started their social media forums, they asked me to be the admin there. And so I was posting over there and then their editorial department learned of me.

Patients Getting Paid and Flexible Gig Ideas

And so they started asking me to write, some articles here and there, POF articles. And then from there now, just in this last two years, I guess, I they've asked me, I write a column monthly called Patients Getting Paid over there so it can build your relationship can build.

So this, takes a couple of weeks, a couple months, a couple of years. What's what's the time frame to build a relationship like that? Is that what you mean?

Well, I've been with them for seven years. I got incredibly lucky right at the beginning that someone. They found me

from my podcast, from the FEMA podcast, because they were interested in starting a podcast.

And this like I said, this was seven years ago. That was very different. There weren't all these podcasts, so they didn't really know how to do it. And so they hired me as a consultant to help them get their podcast up and running.

And from there they said, oh, well, we're thinking about starting this app. Are you available? So I don't I got incredibly lucky. I wouldn't say this is a roadmap.

I wouldn't say this is typical, but getting a gig writing with, you know, and every day help, let's say, or web MD once you're in with them, as I said, there's a content monster that needs to be fed all the time.

And the beautiful thing for patients is they need you. Obviously more than you need them. So there's going to be opportunities available and you get to decide when you're available.

And so for our listeners who are thinking like, I wonder if this might work for me, what sort of suggestions, do you have? I would go to the various sites that you might be interested in, every day.

Health Rvo health, health line, WebMD. You could just do a Google search on health information, online health information companies, and then usually at the bottom, their websites, it will say contact us here.

And if you click in there, oftentimes it will say editorial. And if you send them an email and just let them know your background and that you're interested in writing, particularly if you've got any writing to share, that's in particular, very interesting to them.

So oftentimes people get a diagnosis now and they'll start a blog just to, you know, document what they're going through. And that's that's acceptable to, well, that why don't we talk about starting a blog?

We may have people. Yeah. We're listening. Like, okay, well, that sounds sort of intriguing, but, yeah, you know that that's too much work. I wouldn't know how to begin.

Yeah, that's something else. We have trainings for that in in patients getting paid also. But it's really it's so easy now back when I started mine it was not at all easy.

I feel like I gave birth to two kids, and then I gave birth to a blog, and then I gave birth to a podcast. Both of those things were really difficult back in the day, and it's so much easier now.

Because they have, websites like through Squarespace and Wix that are already there are templated sites, so you're not having to code anything. You can sign up for an account and I, I couldn't swear to this, but I think at least one of those is totally free to sign up for now.

And it just walks you through it. It's very click, point and click and just start typing and, you have birthed a blog, which is a great way to start because not only then are you building a portfolio, right?

And you can start building your readership, your followers, but also, you can monetize that separately yourself because, you can do what's called Google Ads or AdSense.

Also very easy to do attached to your blog. And they place they place ads on there for you. And you get paid based on how many clicks you get on those, for instance.

Okay. And then, would you suggest, that people have an editor, go through what they wrote before they posted? What do you think? You know, I say, just jump in, get your feet wet, see what works.

If you have some friends that you trust will be honest with you, that's probably a great way to get somebody to go through your writing first, because you really no one can edit themselves.

You see on that screen what you meant to put, not what you actually wrote often. So that's helpful. I certainly tell that to our medical students. Everybody in the lab, you can't edit your own stuff, just rewrite it in one session and then come back on a separate day.

And read it again. A tip, that we give our, medical students, undergraduate students is read each line from the end of the article, line your sentence by sentence back, and you'll be much more likely to catch what you thought you said.

But yeah, what you actually said are often just a little bit different. They said a little tweak. Yeah, I completely agree. And for me it's I read it out loud.

Yes. Sometimes very helpful. Yes. And when I've been fatigued or Acog foggy and I really need to get this article in, I will actually record myself reading it.

And then I listen back and that is often where I catch them. Yes. That that is and when you again, for the listeners, when you read it out loud, you can try to do very soft, very quiet, very fast.

Don't, don't do that. Read it like you are projected to the back of the room, with some emotion and some volume. And, I think Kathy suggestion to record it will, will, really be very, very helpful.

And for anyone who's trying to get started and you don't have the money to pay for an editor, you don't have friends that you can readily ask, to help you edit.

These two tips will be, you know, just profoundly helpful. Line by line, backwards and reading it out loud, read it out loud, not muttering, but actually reading it out loud with a fair amount of, volume and emotion.

Will be very, very helpful, I agreed. One more thing I wanted to share to once you kind of have gotten your feet wet in this and feel confident about your writing is something else.

It's really emerging. Now. That's getting very popular is newsletters. Now I have a newsletter, the FEMA six Pack. I have had it for six years. I really did nothing with it, honestly, other than I shared it with the people on my email list.

Writing, Blogging, and Newsletter Monetization

Now I'm growing it. And newsletters have it's full circle. Used to be a thing, then it wasn't. Now it is again. And so many companies are doing it. These email newsletters.

And the thing I like about this too, is if you enjoy writing and I'm not suggesting it need to be about your condition, it can be about, you know, you can monetize your hobby, something you know about.

You actually won't believe that you're an expert, but you really are. Just one step ahead of somebody else makes you the expert. So you can start a newsletter on anything and build your audience.

Right? And then you can monetize it either, do subscription where people pay you, for the newsletter or as I'm doing ads. So companies purchase ad space on your on your newsletter.

The other thing I want to mention is curated newsletter. So for those folks who are really interested in something but maybe don't feel like they're writers, you doing the research for others and providing it in a convenient format people are willing to pay for.

And so our companies to advertise on that newsletter. So my Films six Pack is a curated newsletter. It's a little bit of an amalgam of things because I am a writer.

And so all right, it's called the Six Pack because it's top six topics and Ms. for this week. So it's articles. It's studies. It's all kinds of it's the top six topics.

I also have products that I recommend for folks with them at. So it's very specific to Ms.. And I do write a little introductory sentence for each one of the, six things, but that's all it is.

It is a curated newsletter. So I'm going out and doing that, finding an article, finding a study that's interesting, and I'm linking it there. So I'm not writing this whole thing.

Okay. So you're doing some research to see interesting topics. Yeah. So it might be a new research hopefully. You've talked about some of mine from many, many times.

Okay. Yeah. Yep. And maybe some interesting products. Perhaps, some cooling technologies. Super interesting. And then maybe you have, talked about a new drug that is interesting.

And maybe you've talked about gardening or a recipe. Yeah, definitely. I and I always start at the beginning with a little story about me, because what I found over these six years is people are really interested.

Oddly, in what I'm up to, what I'm doing. So I always start with, you know, the holidays were great, but I'm so happy to get back to this and my misbehavior didn't.

And here's a tip that I found, you know, for decorating, for instance, I don't do it all in one day anymore. Those kinds of things. Just a little hello and then let's get to it.

And here's the top six things. And my product recommendation for that month. And really quickly those product recommendations are often times affiliate products.

So for the listeners that aren't aware of what that means, an affiliate product is you can either have a relationship with the company, that produces that.

So for instance, you just referenced cooling products. So, you know, if there's a cooling vest that you really like and by the way, anything that you're going to promote, you really need to have used it and like it because people can see through that.

If it's just for money, that's silly. Don't do that. I protect my community at all costs. I would never put anything in front of them that I don't try myself anyway.

You can have a relationship with that company that produces the cooling best, and they'll give you, a unique URL that you put right there. And anyone that clicks from your newsletter or email.

This could just be an email that you send out over and purchases something from that site using your URL. You will get a commission for each one of those, and it won't cost your readers any more than it would if they went directly.

And, I presume, let's clarify if you are using an affiliate link, that you're also telling your listeners that you have an affiliate relationship. Yes. Not always. Yes.

Yes. That's required. FTC requires that. Absolutely. Yeah. And the other kind of the most basic where I was we did a training on this and also but the most basic type of affiliate that I tell everyone to start with is Amazon affiliate.

Actually they're called Amazon Associates. Now you sign up for this, program and then you get this unique link, that you can send people to. So in other words, I might find let's use your cooling vest, example again, I'll go on to Amazon.

I'll find the cooling vest that I like. And I click on that. And there's a bar across the top, because I am an Amazon associate that allows me to grab a link.

I think that's the verbiage they're using now. They change quite often. And when I do that, it assigns my personal URL as an associate to that specific product or category of products.

And I can grab that and then put that for instances in my newsletter. So when people click on that from my newsletter, I would probably have a picture of it.

A little description this I use this I really like it. If you're interested click here. They click over. It brings them to Amazon. The nice thing about that is people have been using Amazon forever and trust it, so they're much more likely to buy something from there.

However comma your your commission percentage is much lower on Amazon, but it's so easy entry I tell everybody start with that. And again if you're using the Amazon link, you certainly have to disclose that.

And then there's a resource for, signing up, for these Amazon. What a great Amazon Amazon associate. And yes, and to do that, do people need to create their business entity?

I know you had too many years ago when I started. I don't know if what's required anymore, I really don't, but I know that they lay it out very clearly.

So if you just go over to Amazon and search on associate program or affiliate program, you know, put the comment out that creating your own business, is not that difficult.

There are some online legal services that can help you create a business entity, in your state, and, can help you get a tax ID number for your business so you can open a business account.

And I encourage people to do that, because, having a business entity, there are plenty of tax advantages for you, and, some legal protections if you want things to be business.

That's right. Some leverage.

Business Resources and Closing Remarks

Yeah, it sounds like a big deal. It's not as hard as you might think. It's also not as expensive. There are a number of online legal services. For example, you just sort of Google online legal services, for your state, and, you'll have many options from which to choose.

And there are tons of free services through the SBA, the Small Business Administration, SBA, gov, in most communities, certainly larger communities, there's an SB, D for Small Business Development center.

And those are great resources. And there's something called Scor, which is the senior core, retired persons within the SBA. And those are people who have retired.

You can search on them for whatever industry that you're interested in. And they become your mentor and it's all free. So that's a great way to go to, you know, you can, contact, if you live in a university town, they your university probably has a relationship with this small business.

If you have a community college in your town, they like, likewise, will have a relationship with these entities and, Yeah. You know, when I decided to start a small business, first a publishing company and then a health information wellness company, I certainly went and visited, these small business people to learn, what I was doing.

And I found it to be, super, super helpful. Oftentimes, those colleges in the area have classes to maybe their adult learning classes or. But oftentimes they're a, you know, business 101 or 6 week startup. One.

Yeah, it was one that I took. And, it was, it was, very helpful and not at all expensive. And I learned a lot, met a bunch of, likewise very interesting, people that were starting things.

So there was a dog walking business, and he's done super, super well, that though, you know, so you get to meet, a bunch of interesting people doing very interesting things. Yes.

And getting hooked up with others that are starting things is building that community is really important. I mean, I think we all learned from Covid that how important community is in all facets of our life, but starting something like a business can be nerve wracking and you're not sure.

And should I do this? And it's, if you can meet people, in the same boat or maybe a little ahead of you, it's great to have those folks to go to and bounce things off of and learn from.

And likewise, they can learn from you and you can just build each other. It's it's it's a good way to go. I realize I should be watching the time we've been talking, quite a bit.

We should we should wrap this up, for news. So, Kathy, how do people find you? Well, your best bet is to go to, Well, my emails Kathy with the cat at UMass now.com.

Or you can just go to UMS now.com. And there's a contact button there. There's a sign up for the six pack there. Or you can find me all over social at phones.

Okay. Well, Kathy, this has been absolutely wonderful. Thank you so much for giving, people a lot of hope. Thank you so much. And thanks for all you do for our community.

Really appreciate your help.