

## **Transcript of Pain 101 Podcast: Patients as Partners**

### *Part 1: Podcast with Leslie Levine*

**Natalie Osborne (NO):** Maybe you can start by giving a bit of a history of how chronic pain has impacted your life, and how you've ended up here at the NAPS pain school in 2018.

**Leslie Levine (LL):** Of course. In 2006, thirteen years ago, I came down with an acute pain syndrome that quickly progressed over the course of days to the state where I was in such agony that I was unable to work and unable to do the many things that were important to me in my life.

So, I was initially diagnosed with one condition that proved to be not the final diagnosis. It took over a year to get diagnosed with what I had, which proved to be a form of neuropathy that affects small-fiber nerves. The pain was quite agonizing. It felt like I was being burned alive on most of my body. And I was lucky to be able to get from my doctors some partially effective pain relief.

Then, after I was diagnosed, it was found that a particular treatment that's effective for autoimmune diseases, namely intravenous immunoglobulin or IVIG, worked for me so that after about three years of high-level pain, I finally was put on IVIG, and it dramatically controlled my pain. I was able to function again.

I formed a support group for neuropathy patients in the Boston area that are commonly afflicted with varying degrees of pain, some quite extreme. And I got active in patient advocacy and patient-centered research, particularly with a group in DC called the Patient-Centered Outcomes Research Institute, or PCORI.

I was asked to participate in the North American Pain School meeting in 2018 by my neurologist, Dr. Anne Louise Oaklander, who's at Massachusetts General Hospital and specializes in pain conditions. So I'm very privileged and happy to be at this meeting.

**NO:** And what's your impression of NAPS so far? We're sort of halfway through right now.

**LL:** It's so exciting to see these young researchers being coached by eminent world-famous researchers in various aspects of the pain field and their enthusiasm and how gifted they are. It's really a positive message for the future of making advances in pain control.

**NO:** You were very gracious to sit down with us at lunch for one of our lunch topic table discussions and give us advice on how we as researchers can become pain advocates. And so, maybe you can just start by [discussing] the importance of including patients more and more in your research design and help to shape your research question and even have input on the feasibility of your methodology.

**LL:** That's a very timely topic right now. PCORI, the organization I mentioned before, has led the way in the United States in what they call patient-centered research, which is research that's organized around findings answers to questions that will guide patient care and let patients make informed decisions about their healthcare.

So, PCORI advocates for patient engagement and involvement in all stages of the research question, starting with, at the very earliest stages, helping plan the design of the research. Patients will meet with the researchers, and the researchers will get the patient's really expert perspective on the questions that matter for that group of patients with that condition.

In the past, researchers have not been typically involved in talking to patients at that stage in the research, and the research designs frequently produce evidence but not necessarily answers to questions that patients find important.

For example, a researcher might get data with scores on various testing, but the patient wants to know, will I be able to work? Will I be able to have a good quality of life? Will I be able to live at home and not frequently be in the hospital?

These are the kind of things that patients can contribute to the research if they're involved in the planning stage. And then patients' involvement in further stages of the research can be very productive for the project. For example, diabetic patients can counsel the researchers on how best to recruit their peers for the research projects.

If a research project is about pain in elderly African American women, there's nobody more qualified than a senior citizen African American woman for telling the researchers how to work with this group of people, and how to invite them to participate in the research and also what would make it difficult for them to participate in the project. These are very important for recruiting the patients you need to do the research at all.

And then, toward the end of the project, the results in the past have frequently been published in medical journals, which are pretty much read only by medical professionals and researchers. And patients may or may not have access to the results of the research that is being done on their disease or condition.

With patient-centered research, patients will be on the team who plans how to get the word out and may be involved in writing up in patient-friendly, non-technical language the results of the research, posting it on social media or other forms, interacting with patient advocacy groups who have newsletters and web sites that can get the information out to that group of people, and even being involved in presentations to different groups in different venues to spread the word on what's been discovered and how it impacts patient care.

**NO:** That's really exciting. And especially because so many people want their research to have a positive impact on patients' lives. And what better way to make sure that happens than to involve them from the very start.

I know one concern that was voiced was people are afraid to get patients' expectations up if they're starting a new drug or starting a new trial or exploring an effect. And that makes them reluctant to, I guess, communicate prematurely or involve the patients. But you responded, patients aren't that fragile. Could you expand on that a little bit?

**LL:** Sure, I'd be glad to. Patients know that some research pans out and some doesn't, and that in general it takes a lot of studies that don't necessarily find a new drug or find something that works to produce one that does work.

So patients are very eager to learn more about what's being done in the field and don't need to be sheltered by being told only about the relatively minor percentage of things that work. They'd be more interested and relieved, actually, in knowing that there's a volume of research by excited, dedicated, committed researchers who are willing to take risks on potential therapies and other treatments that may or may not work but that may produce some real change in treatment options.

**NO:** And so the topic of this NAPS meeting has been about the future of pain treatment – “to boldly go.” So if you were to forecast 10, 15, maybe 20 years in the future, what's the ideal relationship between patients and researchers, maybe clinicians, maybe government organizations or policymakers that you think would be the best-case scenario that we can work on?

**LL:** I hope it's not going to take 10 or 15 years. I think the future is now and that things are happening now. I've heard how in Canada and Europe they seem to be further ahead on this pathway than the United States is in terms of having patient partners – true partners with the clinicians and researchers who share, who collaborate, who brainstorm together and bringing the patient's expertise – there's no one more expert on their conditions than they are – along with the clinical perspective and the researchers' ability to delve into new frontiers, all working together to change lives of patients.

**NO:** Great. Well, that's really exciting stuff. And thank you so much for sitting down with me today.

### *Part 2: Podcast with Jacques Laliberté*

**NO:** Okay, Jacques, thank you so much for sitting down with us today. I was wondering if you could start by telling us a bit about your personal experience with chronic pain.

**Jacques Laliberté (JL):** Yes, I can tell you that. First of all, I'm telling you that I was 50 years old, at an age when I should have become a little bit more mature and responsible, but I decided to go and try what I saw the youngsters were doing so well, which is snowboarding at our ski place in Quebec City. I did that, and I was with an instructor and I missed a turn and went over and fell on my neck, and I felt I nearly broke it. As it turns out, it was multiple herniated disks, which eventually can get repaired or that are so sensitive for a long period of time, or for the rest of your life.

When this happened, I nearly lost consciousness but I was okay. I took the board off and went back to the condo and came back to Montreal. A couple of days later, three days later, I was bedridden. That's it, simple. Don't know why, how, but I know that it hurt, and that the radiating was going down my shoulders and my whole back was hurting. So, I didn't really know that it was my neck, or my back or what it was.

I was bedridden for about three months, and then, a friend of mine with whom I play tennis, who's a neurosurgeon, lived a couple of blocks from my place, and we were friends. He came over to see me. He would give me some cortisone shots in my back. My wife would actually pen where it hurt, and she'd put an X and he would come, and I had the cortisone in my fridge and he would come and do this. But it didn't do very well, it did not improve. For me to be able to go and sit down, to just have a bowl of cereal or something like this, I always had to have at least my left arm up in the air, otherwise, it was unbearable.

I spent the time in my bed. That lasted another three months. Six months in total. Finally this friend of mine said he was going to get me to an anesthesiologist who would do an epidural, a cervical epidural on me, and then he said, hey, if he misses, you're a paraplegic. And my answer was, is there pain when you're a paraplegic, because I was living between 8 and 10 on the scale all the time. It was really atrocious.

He said, no, there's no pain. I said, that sounds like a great deal. So, we'll do that. So I did go and meet with an anesthesiologist. He said to me, do you have any questions? I said, yes, one. He said what is it? What's your score? He said 100%. I said, you're my man, and he said, you can't move, don't worry about moving, I've lived in enough pain now, I could stand anything.

Interestingly enough for me, when I was in bed, bedridden, all the things that we talk about with pain, people living with pain, came to my mind. I mean, at one point in time I was saying to myself, I wonder what the sign is going to be to let me know that I'm in depression. I realized that. So, I was kind of starting to analyze that in that fashion. I knew that I was in trouble, but after I had that epidural I was able to start my life again, slowly. And I have been told that I have to listen to my body, that I was not going to be the boss anymore. That was difficult for me to accept, but it worked.

There are certain things that I can't do anymore. For example, I can't ski because of the compression. Cycling is something I cannot do, and I enjoyed at one point in time in my life, but I cannot do that anymore, especially with the Quebec roads. They're even worse. My wife is a cyclist, and when she comes back from a 50-kilometer ride, she tells me, Jacques, this one wasn't for you, for sure, for sure.

That's what I did and that's how I ended up being a chronic pain patient. But today, I play tennis, I can play two hours of doubles, a couple or three times a week. I'm having a good time doing this. But I found time to relax myself. I don't spend six hours at the computer in a row. I balance my activities with relaxation and be careful. But otherwise, life is good.

**NO:** How did you first get involved in patient advocacy?

**JL:** When I met the doctor, [for] the epidural, he asked me, he said, you know, we professionals go and meet with government for continuum of services for patients. When we meet the politicians and all of the people that we meet in government, they always say, where are the patients? So he says, we're trying to set up an association of patients, so that we can have patient representation when we go and meet these people. He said, would you represent our hospital at that first meeting and see how it goes? I said, you know, if you improve my life, you're going to have my services with great pleasure.

I didn't hear about a thing for about six, seven, or eight months, and then all of a sudden, I got a phone call. They said, we're going to be having a meeting, would you come? Yes, I will. I said I would, I will.

They explained to us how this association would be built up and would get started. There was somebody already wanted to be president and that was fine with me. I would participate but nothing more. The person that was going to be president decided at one point in time that he could not follow through. So, everybody turned around and said, Jacques, wouldn't you like to be president. I said, I'm not sure, but I can certainly help.

I wrote a strategic plan, a business plan really, for the association, and I created that plan and presented it to everybody. Some of the people in the group didn't even know what it was to be on a board of directors. We had to start from pretty far. Then, we built it. Our first meeting, with members, we were just about 11, which is the total number of people on the board of directors.

The following year we had 1,000, a couple of years later, we were 4,000, and then now today we have 8,000 members. The Quebec Pain Patient Association is the association that deals with the government and is a major stakeholder with others, like scientists, and other health professionals, that are on a panel. Together we created, with the government what is now structured, to ensure continuum of services for the patients.

**NO:** What can other provinces learn from that cooperation that you have with the expertise centers like University of Montreal, Laval, Sherbrooke and McGill, and the regional centers?

**JL:** Originally, we didn't even have that, so we've come a long way. The reason why we were able to achieve this is that, although we weren't a real coalition between QPRN, the Quebec Pain Research Network, or the L'Association québécoise de la douleur chronique (AQDC), which is our pain patient association, we worked really as a coalition, although we weren't officially one. But, you know, when you have a common goal and you're moving forward together...because we work so well together, we were able to achieve what we've done.

I think that somebody has to take the lead at one point in time, in any province...Pain BC is doing a fantastic job, and they're trying to do exactly that. But all within Pain BC. So it

will be an official coalition once it's achieved and that's a great organization. They work with government and then they can get things done.

Other provinces should do the same thing. It's not so hard to do. But, on the other hand, all it takes is good will.

**NO:** We really appreciate to get your business acumen and your advice on why it's in a researcher's best interest to include pain patients as partners, and why it's in their best interest to make their work accessible to the patients.

**JL:** You're asking the right guy. I've been at it for 15 years. Essentially, it doesn't come overnight. It's a work in progress. I've seen a big evolution and now, we're talking about having a patient being a partner but not a scientist. We're no scientists. You know, sometimes a lot of us refer to pills as being yellow or green or blue. But, if the researchers can target on really the patient's needs, rather than go off and try to do it alone, and then not being focused on what, really, a patient needs, I think it's a little bit more difficult to get funding now.

You said it before, I'm a businessperson, I get a little mercantile side to me, and I've had it for years. But I think that from a practical point of view, it makes sense in terms for researchers to go and get dollars. If you're without dollars, there's no research. It's pretty darn easy to just move on with that and say okay, what is it for the researchers to include patients? Well, if you set up the original set up with the patients, it's clearly understood that they're not scientists or doctors, once the parameters are well set, I think that we can work as teams.

Every time I've seen that, I've seen patients that were empowered, I've seen researchers that have been able to accomplish better work, faster, and a term that maybe you don't use all the time but, "return on investment." Which means that if you spend so much money to do research, when is it going to start producing real results in the field. So, really, I think that's where we're at now. I see this as only improving over time.

What I liked about the NAPS session that I attended all week, is that the youngsters that are there, and I call them youngsters because I'm 73, but the idea now is that you're going to carry this. And I really mean it when I say that, when I've said it during the conference, you're really going to make a difference, and we'll be alongside.

**NO:** Maybe you can talk about, from the patient perspective, how it affects the lives of patients when they are included or when the results of the research are made available to them.

**JL:** When we started having a Facebook site for the association, we were really concerned about people who would start writing things about pharmas that didn't give them the right pills to cure them, and we would get a lot of negative comments, and everything would go wrong.

At about the same time, we had one person that was suicidal and kept calling us with suicidal, not threats, but cri de couer. You know, when we ended up having our Facebook site, this person turned into a helper for others. You know, from our perspective, the beginning, or the light at the end of the tunnel, and every time I meet with patients, what they want to know is, where are we going, what's being done. They're not too concerned about which research is doing what, to begin, but the first thing they say, okay, what's in it for me, what are you going to do for me so that my life gets a little bit better.

Nobody is looking for a cure. So when we see this, it makes a difference. I don't know that it's a placebo effect, but surely, it makes a difference because hope, you know, that's fed and well fed, is something important to the patients.

That's why they need to be included, because then they get to see what's going on. That'll give them and continue giving them hope. For us, it's very important. That's why, during the conference I was saying to you guys, announce the research you're going to do. Present yourselves with that piece of work that's going to be done, and halfway through, publish halfway results, it's okay. It's all part of the buildup. Look at politicians, they do that very well.

**NO:** Well thank you so much for sitting down with us. I will look forward to hearing more from you in the future, with all of the many committees and councils that you sit on.