Interview with Gilliosa Spurrier

Transcription

I’m Gilli Spurrier-Bernard. I am a patient advocate because my husband is a stage 4 melanoma patient. As a patient advocate I initiated the Melanome France group because there was no national group. I run the group. I run the forum. I liaise with other stakeholders and pretty much just make a nuisance of myself if I possibly can.

It first started I wanted patients to go to the centers of excellence. In melanoma, which is quite rare, there aren’t that many centers of excellence even though some centers actually claim that they are centers of excellence. I made a website that just showed the sites where they did the biggest number of clinical trials because I couldn’t actually say this is a better center than another. I just thought I would just put where the clinical trials are held and which centers have the most. That way patients can decide for themselves where the expertise is. That was my first touch with advocacy at all because I was so angry that people were dying when they thought that they were getting equal treatment across the country because it’s France and everyone gets equal treatment. In actual fact this wasn’t the case. That’s the way I started.

I’m trying to empower patients to just speak to their doctors in a manner that’s useful to them because very often they go in, they’re shocked by the diagnosis. They ask no questions. They don’t realize that they’re supposed to ask questions. They go out and then come to us on the forum and say, “I didn’t understand a single thing I was told.” Then we spend hours teaching them on the forums how to read their pathology

reports, how to understand what their doctor's telling them, what they should be expecting as a standard of care. It's a huge force I think when you have 4 or 500 patients going through the same thing to be able to tell you that what your doctor's telling you is not right or it has not been told you in the right way. I think it was just a huge revelation for me because I was someone who hated Facebook.

I was someone who never thought that forums had very much value and yet this forum has changed the way patients gather data. We gather quality data because it's a private forum. Patients can say what they like. They're not condemned to saying to their doctor what they think they should be saying. They can say what they actually really should say. We actually get really high quality data. And we learn. It's a learning process. We see ourselves a little bit like a startup. You have an end goal that you want the best treatments and the best experience for patients. Then you work out what you need to do in order to get that. We do it well sometimes and badly sometimes. But we learn. We're happy to do it this way.

Initially the forum was an open forum. We had very little exchange of information. There was lots of people saying thank you for the information but there was no discussion. We closed the forum and suddenly we had engagement. We had people saying I don't agree with this. We had people just basically giving their own experiences in a far more open manner. I think it's just empowered patients. I see patients, one patient would come back to me and say, "I went to my doctor today and do you know I asked 5 questions." For me that says it all. That's just the pinnacle.

HOW HAVE YOU BEEN INVOLVED IN CLINICAL RESEARCH AND TRIAL DESIGN?

It starts as an industry feedback because one of the first approaches industry does is come to us with this very American

idea that they can ask you to recruit patients for their trials. This was a strange strategy for me because I then said but why would … If you have a problem recruiting patients to your trials – if the trials were good in the first place you wouldn't have a problem. They were basically trying to use the patient organisation as a recruiter. The first thing I was doing I would look at a trial and say why I wouldn't do it as a patient or what the issues were going to be for patients.

I try and encourage patients to report their side effects, to truly report their side effects. It would be even better if their clinicians would actually take seriously sometimes this reporting. Sometimes it's too much trouble for them to have to do their paperwork if you like. Yeah, clinical trials, it's just unavoidable in melanoma because that was our only treatment. Now we're starting to have treatments that are approved. The paradigm is changing a little bit. Still we have some very poorly designed clinical trials. I have actually done a journal club that we use in the European network where we actually take apart the clinical trial that is being done, a phase 3 clinical trial, why it was good, why it was bad, where they missed opportunities. It's vital for patients to be able to argue these points.

I have this huge faith in patient-generated research. I think we are often rubbish at it initially because we're not trained in it. We don't know about statistics and what's going to be accepted and validation and all this kind of thing. This stuff, I hadn't a clue about before. Then you start realising that you collect very good, quality data from the primary data source when you're dealing with patients. This, for me, as a scientist, I was a geologist, but in science you always go to the primary data source and that is patients. If only we could collect that data and use it for our own research I think we would cut away a lot of the stake hold interest that goes on around, even though we have these systems that they say are patient centric, we would cut away because we would have high-

quality data to say it’s quite wrong.

I have seen it in many of the other disease areas where they’ve done it much better. HIV is a perfect example. In the CML field where they basically prove that adherence was not what the doctors were claiming it was, this is critical stuff for patients and for the patients that were going to go on these treatments in the future. I would really like for us to get much better at doing good research. I think that’s the future because then everyone will have to snap into line and treat us as a proper stakeholder because we are the ones with the data and we are the ones that are learning how to use our data for our own benefit, not somebody else’s.

HOW DID YOU BECOME INVOLVED WITH EUPATI?

I heard about the EUPATI course just halfway through the first year. I said to myself, “I just wish I had done this course when I was trying to battle my way through a total lack of knowledge, but I was having to deal with things that I didn’t have a knowledge base in.” I said to myself, “I’m going to do the next one.” It would have been far better for me, and probably the organisation and some of the interactions I had, if I had done this course the year before. That’s how our disease was developing and how our access to drugs was developing. That’s how it was.

It’s just been a revelation to me because it slots in all the different stakeholder perspectives and interests. The whole development process is really important. You can argue this. You can argue this in front of your doctors. If there’s under powered clinical trials or something and they’re trying to claim that you should be on this trial and you say but the early data was not really good because it was under powered. Just things that I would never had been able to say when I was trying to argue the same thing a year ago because I just didn’t have the knowledge.

But it does actually spur me on to being much more involved in the country specific angles on it which doesn’t get so much covered but now I want to take the tool kit to take out parts of the tool kit and French-ify it if you like, so really make it applicable for the French patients.

I’ve really benefited a lot from it. I hope they carry on doing this because an empowered patient, a patient expert, is as important in the process as any other stakeholder.

We can’t sit back complaining that we’re patients and how can we know and oh we don’t have any time and it’s just unfair and we’re suffering our disease. Nobody else is going to do it for us. We just have to do it ourselves.

We cannot sit here moaning that we’re not educated and we don’t have the background and we don’t have the time and we don’t have the resources, we just have to get ourselves educated. And this is the perfect facility for doing that.