

Q : Do you think that the European research is different from the American one ?

A : Well, difficult question ! we have different approaches in Europe, there is a greater variety of things we are looking in Europe than in America. In America, it is more straightforward and they are focusing on all the same things. Here the variety is given by the different countries, which is a great chance, we need more collaboration, but there are projects now in Europe that give us opportunities for such collaboration. I think we are stronger than the Americans, but the difference is that we also have to collaborate with the Americans because they have different types of patients than we do. They have the Hispanics, the non-caucasians. But that also means we need a specific scientific European approach because we have different patients, we cannot just adapt what comes from the Americans and the Americans cannot just adapt. We have to modify, we have to adjust to the different disease expressions in different parts of the world.

Q : What is the add value of a congress like this one ?

A : We need each other to exchange and find new ways to collaborate. That's the best occasion in such a conference. The size of the conference is also important because most of the people here know each other, and so it is not a difficulties to enter in contact and to involve new ones ... I'm just coming from the poster session and I have seen young people doing research and publishing new things about different aspects. So we will bring them in the family of the researchers of lupus in Europe and give them the opportunity to collaborate with the others. So it is a good way to exchange.

There are a lot of things that is repeated. If you look at the talks, most of the things are published, it is known, but still, there are minor things in there that people address differently, and then you can discuss it, you can talk. That is a chance here and that is different than, for example in Eular, where you have a session on lupus on a day and the next is on the other day, so the people spread away immediately and there is not much time to discuss, and no chance to meet the same people during the breaks and continue the discussions about specific topics. I had for example a discussion today on treat to target¹, and there was provocative discussion yesterday, to find where there is a problem, different aspects, to see what can be the next step in this process. And there, being able to talk with people that see it different is helpful.

Q : What is the news since the beginning of 2014 ?

A : The paper on treat to target. It's a thing that will be discussed a lot. There was the question yesterday of whether it is the time already now for something like that. There was a worry about normalizing the patient, and not look at the heterogeneity of the disease. All these discussion is still to come up, and then we can see how we make the best out of it. For me, it is very important that we have targets, whether one or more can be discussed, it is another story.

If you go to your physician and he says I am giving you now X, Y or Z medication, and he does not tell you what he wants to reach with that, then you don't know after 6 months whether it happened or not, because he did not tell you what he wanted to reach. If there is a diagnose for lupus, any physician then tells you "this patient will be on steroids for his life", but if you go now and say "I want

¹ See : <http://www.medpagetoday.com/Rheumatology/Lupus/45326>

to go for lower steroids” and this is now your target, then each time you meet, you can review where you stand versus your target, and is it time to reduce now, or what. And that is aiming for something.

I am also a coach for targets, in a psychology way: if you have a target, and you believe in that target, then you do everything to reach the target. Even things you don't have in mind are targeting. And that is the difference between no target and a target, and that is influencing your story.

It is not about me as a doctor telling you “you are my patient, I tell you your target is in 6 months no steroids”. If the patient is not believing that, I will never reach the target. To speak about the target, I propose it to you, and we can speak about it, you can imagine and then we can go for that. It is very important to bring the patient in the boat. But if you have no target, you don't need to go for something. It is an important process, and an ongoing process. For 2014, the importance is not in that paper on Treat to target, there is nothing new in there, but it is bringing it to the point of doing the next step. Small steps, what is the next step with the patient, ...

I remember for example when we started in Germany to standardise score documentation, we recognized that only 20% of our patients in steroids get an osteoporosis prophylaxis. Then we addressed that in public, and after 2 years 80% of our patients got osteoporosis prophylaxis. You address a specific target, you say this is our target, and you work it. We say every patient should be on antimalaria, then you look at every patient, and if they are not on antimalaria you ask why, and there must be a good reason for that.

Q : For us as patient organisation, what should be our target?

A : We talked that when we worked together on Lupus Europe's strategic plan, and I said every patient should participate in research. You are all unique, and therefore you all must participate at improving our research and knowledge.