

Interview of Professor David Isenberg

B- What is the interest of such a congress for Europe?

Dr I. - Lupus remains a very troubling disease, whether it happens in Europe or anywhere else in the world. Clearly, there are now in Europe many ethnic minorities in which lupus is more common, so in the UK for example, we have now very significant Afri-caribbean population, very significant south east asian population: so in my consultations in London for example, I have seen 650 lupus patients over the last 30 years and 40% of those patients come from ethnic minorities. The same sort of things happens in other parts of Europe. We need to be aware of lupus both for its own sake as a disease which can affect caucasians as well as other groups but we are mindful of that it can be more severe in these South East Asians and Afri-Caribbean groups which are now more present in many parts of Europe.

B- What do you think is the most important news in the beginning of this year 2014?

Dr I. - I think it is very exciting, even if it remains to be confirmed through clinical trials, that it might be possible to treat lupus and even lupus nephritis without steroids. This is some work that is going on and is undertaken principally by a colleague of mine, Dr Lightstone (?). The idea is you can use B-cell depletion at the start of the treatment of lupus. I was first to use Rituximab to treat patients with lupus 14 years ago, and we were only allowed initially to treat patients at the end of the lupus line, i.e. patients that had failed with conventional lupus therapy, some 10 to 15% of them. Dr Lightstone said : "if it works at the end of the lupus line, why not to treat patients with that at the beginning?" So she has been starting to treat lupus nephritis patients, as soon as the diagnosis is made, and we have assembled numbers. Essentially the exciting news is that (a) it is effective: you can follow those patients by using Rituximab on this type of patients, followed by Mycophenolate followed by Azathioprine and (b) not only it is effective but also it allows to substantially reduce the use of steroids. Steroids overall is a wonderful drug in the peak situation, but long term, we all know it can create a great deal of problems.

B- What is the major problem now for lupus patients?

Dr I. - There are a number of problems. First of all, the problem of making the right diagnosis, and I have seen a number of patients where the wrong diagnosis was made. Sometimes, it is not the fault of the physicians. For example, some patients may present very low platelets, so we think of a sign of Purpura, and we think that about 15% of those patients will go on to later develop lupus. But we have no way to know which 15%, so that is a challenge for us.

Lupus can present a variety of different problems, it can be mistaken with rheumatic arthritis as a classic example, so making the right diagnosis quickly remains a key problem, and that requires a lot of education. We need to make sure that our general practitioners, primary care physicians, are familiar with the diagnosis and must think at it particularly with young women. This is very, very, important. Secondly it is hard to treat lupus patients. Third, we have the ongoing disappointment of medical trials in lupus that did not work. Fourth, we have the situation that even when clinical trials have worked, like

Benlysta, some organizations like NHS don't approve the drug either because of cost or because they don't like the data very much, so in some countries Benlysta is used very widely, in others like UK, it is not used at all... So, there is a range of problems.

And pregnancy remains an ongoing problem, because Mycophenolate which is a very effective drug for lupus is not recommended during pregnancy, so you have to switch back to Azathioprine which is not bad actually, but clearly some patients require something stronger, so managing a pregnant lupus patient is quite a challenge as well.

B- What message would you have for our members?

Dr I. - I have several. First, I am convinced that lupus is being recognized earlier by our physicians. I am convinced that there are an increasing number of physicians, rheumatologists, nephrologists who are very interested in lupus, want to be helpful to patients, and are aware of the complexities of lupus. I think we have reached the zenith of how we can treat our patients with currently available drugs. I think the future is encouraging because there are a range of new biological drugs which at least have the prospect of delivering better quality care for the patients with better outcome, and increasingly we are aware of the long term problems of lupus... that is not the same as being able to do much about it but at least we can seek to avoid the hypertension, or osteoporosis for example. There will always be further issues but at least, there is awareness and better treatments for patients.

B-What do you expect from us as Lupus Europe

Dr I. - It has been a very productive connecting road between the patients, yourselves, the physicians who are interested, and those doing research. I think the things must continue. The best way forward is to make sure we are working together. Communication is the key really. When former British Prime Minister Tony Blair came to power he said the most important thing is education, education and education, and I think it is true, but also communication, communication and communication.

B- Well, thank you for communicating with me!