

LupusAcademyNewsletter

Issue 2

November/December 2013



Welcome to the second issue of the Lupus Academy Newsletter. In this issue you will discover a brief history of the Lupus Academy, a report from the Buenos Aires meeting and our future plans. Also find out more personal insights from Professor David Isenberg, co-Chair in 2013.

Second annual meeting in Buenos Aires

The Lupus Academy 2nd annual meeting was held at the Hilton, Buenos Aires on 17–18th April 2013. We provided full continuing medical education (CME) accreditation and a highly interactive educational forum that shared best clinical practice and dissemination and discussion of cutting-edge research.

Topics focused on genetics, outcomes, fatigue, biologics, infections, pregnancy, nephritis, T-cell signalling, interventional strategies and immunopathogenic mechanisms driving systemic lupus erythematosus (SLE). The disappointing outcomes of early biologic trials and recent successes of B lymphocyte stimulator (BLyS) and B-cell activation were presented and this will enable more rationally designed future trials.

Over 95% of attendees felt that the meeting met their overall learning objectives with relevant content delivered in an interactive way. CME programme feedback was very positive, of good quality, high educational value, had a truly independent feel and no commercial bias.

Save the date

Our 3rd annual meeting will be held on 7–9th March 2014 in Berlin (more details to be announced soon).





Brief history of the Lupus Academy

During the 8th European Lupus Conference in 2011 in Portugal, six international experts met to discuss the need for an independent CME-accredited education initiative in SLE as options were limited. These clinicians wanted an independent and highly interactive global educational forum that enhanced clinical management of lupus. A Steering Committee was formed, sponsors were found to fund this global CME initiative and the Lupus Academy was born.

In mid-2011, the Steering Committee selected and appointed various support organisations to help with the development of the inaugural meeting of the Lupus

Academy in Barcelona in March 2012. Following delegate feedback, the sponsors agreed to continue funding and a second meeting took place in Buenos Aires in April 2013. An additional three experts joined the Steering Committee and they bring with them different clinical experience and / or represent new geographic areas including South America and Asia. In the future, additional experts will be invited to join the group plus the scientific programme will be continually adapted to meet educational needs.

Material has already been developed for the second meeting in Berlin in 2014 building on the strong foundations laid in Barcelona and Buenos Aires.

The Lupus Academy: What does the future hold?

The future is bright for the Lupus Academy and more educational opportunities are planned for 2014.

The extended Steering Committee

There are currently nine clinicians on our Steering Committee and some colleagues from North America will join soon. These clinicians develop the scientific programme for future meetings plus CME courses online. Our highly interactive forum allows the exchange of information and experiences in lupus. Initially confined to Europe, the forum now incorporates insights from Latin America and Asia-Pacific.

Educational programme funding update

For 2014 and beyond, we hope to acquire multi-company sponsorship. This will allow us to continue our impartial and balanced CME programme as well as expand our activities to reach even more clinicians worldwide.

Breaking new ground in the Philippines

In a new venture for the Lupus Academy we are extending our programmes to reach the Asia-Pacific region — in the Philippines!

Despite the recent unfortunate disaster, the 'mini' academy aptly dubbed "Asian Lupus Summit" by the Lupus Academy, will be in collaboration with the Asia-Pacific League of Associations for Rheumatology (APLAR) Congress and held in Cebu, the Philippines. We hope to be able to release details of this meeting soon, but in the meantime, keep the dates 31st March to 01st April 2014 free!

Lupus Academy Steering Committee (2013–2014)



Ricard Cervera



David Isenberg



Munther Kamashta



Roger A. Levy



Sandra Navarra



Ronald van Vollenhoven



Thomas Doerner



Andrea Doria



Zahir Amoura





Meet the experts – 2013 Meeting co-Chair Professor David Isenberg

Interview with Professor David Isenberg, MD, FRCP, FAMS

Our key goal has been to bring clinically relevant education in lupus to a broad group of clinicians. Our overall long-term objective is to establish the Lupus Academy as the main global provider of CME in this field.

In 2012 and 2013 we had an annual meeting in Europe and South America, respectively, which provided a mixture of informative presentations and interactive workshops. We obtained feedback from participants on the most relevant topics for future educational events and/or materials. The plan for 2014 is to extend this kind of programme to other areas and we are hosting a 'mini-Academy' meeting in Asia (following another European meeting). We will also extend our Steering Committee to include representatives from North America.

Our vision for the future is to maintain our core annual meeting and extend our geographical educational reach via 'mini-Academy' meetings in other regions, in collaboration with professional congresses where possible. We will develop educational and e-learning materials from these meetings, which should allow more clinicians to access our educational materials on lupus. In addition, we'd like to create a more permanent university-endorsed educational course in lupus.

What format will future meetings take and why was the Barcelona meeting an independent event and the Buenos Aires meeting a pre-congress activity?

These different approaches allowed the Steering Committee to compare the benefits and drawbacks of both types of meeting. After careful evaluation we have come to the conclusion that for our annual meeting, an independent meeting is the best option. This avoids the perception that the Lupus Academy is 'just another satellite'. Independent meetings are also more cost effective (per capita costs) than holding the meeting in collaboration with a congress. They also help to focus the minds of the attendees.

The Steering Committee has also expressed a preference for the audience to include a significant number of younger clinicians, and we feel this is more likely at a dedicated event rather than a large congress as funding to attend these events is often limited to senior colleagues. Unlike most other meetings the Lupus Academy covers meeting expenses for younger doctors and this provides one of

the few opportunities for them to attend a higher level educational meeting.

For 2014 we are planning to run both types of meeting; Berlin as an independent meeting and a one-day pre-congress activity ('mini-Academy') at APLAR, with the content taken almost verbatim from the annual meeting.



Professor David Isenberg

How do you think the Lupus Academy fits in with the SLE educational activities from professional associations such as EULAR and the ACR?

We feel that while the activities of EULAR, ACR, etc. give a good introduction to lupus, there is still a significant unmet educational need in the area of lupus. The Lupus Academy provides a dedicated voice in this increasingly important disease area and offers a more specialised education for people specifically active in lupus. Our activities therefore complement the more general activities of the major conference organisers.

Were you given any feedback at the last meeting about the benefits of the Lupus Academy to clinicians?

Clinicians participating at both meetings have told us that they particularly enjoyed the highly interactive nature of the Lupus Academy meetings. In addition, the efforts provided by those giving the basic science talks to make their contributions intelligible was much appreciated.

What difference do you think the Lupus Academy has made for patients with this condition?

As a former British Prime Minister once said 'Education, education, education'. And this applies to clinicians treating patients as much as to the patients themselves.

What do you think the future holds for patients with lupus? How do you think these patients will be treated?

It would be good if in 10 years' time, as is the case now for those with rheumatoid arthritis, a range of biologic drugs is available to treat our patients. These drugs will have been

shown to be successful in major clinical trials and priced reasonably so that they can be used world-wide. We also hope that the message “the best use of steroids is the lowest possible dose for the shortest possible period of time” will be universally accepted.

What first attracted you to the study of autoimmune rheumatic diseases and lupus, Sjögren's syndrome, myositis and antiphospholipid antibody syndrome?

Serendipity! As a young Registrar, I admitted a patient with acute rheumatoid arthritis overnight to a general medical ward at University College Hospital where I was working. The then newly appointed consultant rheumatologist, Dr Michael Snaith, came to see the patient the next day when I happened to be on the ward. We got chatting after he had written the patient's notes. He “sold” me the idea that rheumatology was an interesting sub-specialty and mentioned that he had just started a lupus clinic. He also mentioned that he had some money over for a research fellowship and if I could go away and think of an idea, he would be pleased to talk to me again. The medical professorial unit that I worked on had a great interest in muscle disease and I had been taught how to do muscle needle biopsies. I did some reading around, discovered that there was a dearth of knowledge about muscle involvement in patients with lupus. I thus wrote my first grant aimed to do clinical assessments of muscle disease in SLE accompanied by muscle needle biopsies which would then be assessed by me for immunoglobulin and complement deposition. The grant got funded and the rest I suppose is history! Pasteur once suggested that “chance favours the prepared mind” but the corollary is that you have to have a chance!

Are there any lessons we can learn from rheumatoid arthritis that we can adapt for lupus?

For me a key lesson which has been learnt is to establish a biologics register to capture the long-term, real life outcome in patients given new potentially exciting drugs. The British Society of Rheumatology established its Biologics Register for rheumatoid arthritis in the year 2000 and now has a huge databank on over 20,000 patients being followed. Very recently, the British Isles Lupus Assessment Group (BILAG) – Biologics Register has been established at the University of Manchester under the direction of Professor Ian Bruce and this is, I believe, a major step forward.

What do you think have been the most important discoveries in this field?

How long have you got? Lupus was once thought simply to be a disease of the skin but since the 1870s its capacity to affect virtually every organ system in the body has become increasingly appreciated. The fine dissection of the

complex pathogenic pathways that lead to these conditions is an ongoing, difficult, but rather heroic struggle. The key recognition that T and B lymphocytes and their many subsets interact with genetic and hormonal influences to give rise to lupus is now widely appreciated. The devil, however, is in the detail and the very diverse nature of lupus speaks to significant diversity of the precise cause in an individual. After all, it is hard to believe, say, that a Caucasian patient who meets the classification criteria for lupus by virtue of having mild arthritis, an intermittent malar photosensitive rash, positive nuclear antibody and low lymphocytes really has the same disease as an African-Caribbean patient with aggressive lupus nephritis, very high levels of anti-dsDNA and low platelets.

The development of accurate disease activity (e.g. BILAG and to a reasonable extent Systemic Lupus Erythematosus Disease Activity Index [SLEDAI] and Systemic Lupus Erythematosus Activity Measure [SLAM]) and damage indices together with health assessment and quality of life questionnaires has given us the tools to help both manage lupus patients and undertake meaningful clinical trials. The widely held view that B-cell depletion is an effective form of treatment (whatever the clinical trials may say) has also given us a new form of treatment beyond the classic steroids and immunosuppressive drugs.

What do you think are the hot topics today in lupus?

The genetic origins of lupus are hot but very challenging topics. Over 40 genes have been recognised to be linked to the origins of lupus. However, their exact contribution and relative importance remain unclear. Optimising clinical trial design is absolutely vital and, simple as the concept might be, the accurate and agreed definition of a flare in patients with lupus still challenges us. The question of why patients with lupus are more susceptible to atherosclerosis and the development of heart attacks and possibly strokes continues to fascinate, but perhaps hottest of all is the issue of whether those drugs currently in clinical trials will be shown to be effective and can be introduced to manage our patients.

Describe a typical day for you at work?

I arrive at 7.30am and I leave between 7.00 and 8.00pm. What happens in between is highly diverse! There is no typical day. Amongst the many things I might do are clinics (two days a week), discussions with colleagues and collaborators, plan meetings, attend meetings, read and write grant proposals, answer innumerable emails and phone calls, read journals (I avoid social media!), amend, write or more when time permits rewrite songs for the band ‘Lupus Dave and the Davettes’ that I perform with periodically!