

LUPUS EUROPE

CONVENTION 2020

report



LUPUS EUROPE

31st Annual Convention

LUPUS EUROPE CONVENTION IN THE CLOUDS

26th - 29th November 2020



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INTRODUCTION

Despite being in the midst of a very challenging year with Covid-19 restrictions, Lupus Europe was able to host its 31st Annual Convention from November 26 to 29, 2020. With the entire world on lockdown the event had to be held online and thus the “Convention in the Clouds” was born. Instead of seeing this as a disadvantage we chose to see it as an opportunity to invite some of the people from around the world, who we would normally not be able to invite to our Convention.

A total of 79 participants attended the convention this year, coming from: Austria, Belgium, Bulgaria, Chile, Cyprus, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Israel, Italy, Lithuania, the Netherlands, Norway, Poland, Portugal, Romania, Russia, Slovakia, Spain, Switzerland and the UK.

Some of the sessions were also transmitted live on Lupus Europe’s Facebook Page. The number of views for each of them are at present:

Lupus & Covid with Dr. Pedro Machado	4711 views
Lupus Europe Strategies & Projects 2020-2021	1213 views
Lupus Around the World	1088 views
Panorama of Lupus Care with Prof. Laurent Arnaud	2564 views
Lupus Research with Prof. David Furie	2487 views
Lupus Skin and Aesthetic Care with Dr. Meelad Habib	1531 views

Please note that the summary below is based on notes taken by board members. It should not be taken as a complete and literal abstract of the presenters’ work and might contain simplifications or unintended omissions. Slides used by the presenters are available for members in the restricted section of our website.

PRE-CONVENTION meetings

LUPUS & COVID

with Dr. **Pedro Machado**



We know how much Covid-19 occupied the minds of everyone at the time of the Convention and being chronically ill of course we all have a lot of questions about how it effects lupus patients. To avoid having too many discussions around this topic during our Convention, which should be a positive experience, we decided to invite one of the people in Europe who knows the most about this topic to speak.

MD PhD Pedro M. Machado is an Associate Professor & Consultant Rheumatologist at University College London (UCL) and University College London Hospitals (UCLH), in London, UK. His research interests include the investigation of new therapeutic strategies and the assessment and prediction of outcomes in rheumatic diseases, with a focus on Myositis and Spondyloarthritis. More recently he has developed an interest in COVID-19 and its impact on patients with rheumatic diseases. He is the Chair of the EULAR Standing Committee of Epidemiology and Health Services Research (SCEHSR), and a member of the "EULAR COVID-19 Database" and "COVID-19 Rheumatology Alliance" Steering Committees.

In his presentation he spoke about RMDs, lupus and Covid-19. After explaining in more detail what Covid-19 is and does, Prof. Machado mentioned that 85% of Covid-19 cases are mild and the patients do not experience difficulties that require them to be admitted to hospital. 10-15% will suffer from severe Covid-19 symptoms and they will require hospitalization and oxygen support. Around 2-3% of those will end up in a critical state and die from complications due to Covid-19. The main factors when it comes to Covid-19 related fatality are; age (higher age, higher risk of death), gender (male gender gives a higher risk of death) and a wide range of chronic diseases.

After a very interesting presentation there was time for questions and answers. Here Prof. Machado was asked questions like...

- *"In the presentation on one of the slides I saw that when you were smoking before and stopped, you were worse off (in terms of disease severity) than if you were still smoking and that puzzled me"*
- *"Is the hospitalisation threshold with covid for patients with rheumatic diseases lower than it would be for the general population." Do we have any idea if this plays a role in driving hospitalisation numbers for patients with rheumatic diseases and covid up?"*
- *"Are you aware of possible correlations between neuropsychiatric SLE (and antidepressive / antipsychotic medication) and Covid hospitalization?"*
- *"Is there a bigger risk for people with SLE using belimumab" in terms of covid?"*
- *"Is there a risk of the mRNA vaccine to us with lupus?"*

You can still watch this session
on the Lupus Europe Facebook page [here](#)

PAN & INDUSTRY workshop

At the occasion of our Convention, we try to always arrange a meeting / workshop for our industry partners and the Patient Advisory Network (PAN), who are not working with the EMA. This year was no exception although the meeting was shortened quite a bit since it had to be online. During the meeting each member of the PAN made a short presentation of themselves, so our industry partners get a better idea of the people they are working with. After that the following topics were discussed:

Questions about life as a Lupus patient during and after COVID-19

- *How did you adapt your lifestyle because of the pandemic?*
- *How has your Lupus care and access to the providers/clinic been impacted? Did you engage with your doctors and nurses virtually? How was that done?*
- *If you did, how do you feel about having to go to the clinic for monitoring or treatment/infusion?*
- *How did the pandemic impact your access to treatment? What impact has it had, if any, on your adherence? Why?*
- *What changes would you like to keep post the pandemic and why?*
- *Has the pandemic changed the way you look at Clinical Trials? Why?*
- *How do you feel about a possible Covid-vaccine? Would you take it? Which concerns/questions would you have about it?*
- *If you had to advocate for one change in your Lupus journey, what would that be?*

LUPUS AROUND THE WORLD

Lupus organisations from around the world presented their activities.

Europe has friends around the world.

- Presentation from LFA / **Lupus Foundation of America**
- Presentation from **Indonesia**
- Video from **Mauritius**
- Video from **Russia**
- Video from **Latin-America**

You can still watch this session on the Lupus Europe Facebook page [here](#)

MEET & GREET virtual drinks

In the face of conducting our 2020 convention virtually due to the pandemic, we decided to include a virtual “Meet and Greet” in our convention agenda.

Usually, our convention would include an element of socialising, whether that be over a coffee at breakfast or a wine at the bar in the evening. We appreciated this would be difficult to recreate in our online platform, so, we decided to dedicate a specific time to this.

To break the ice, we asked the attendees to tell us two things about themselves. One would be true and one would be false. This was a great way to get the conversation flowing and to include everyone.

We learnt a lot over the two sessions ranging from previous hair colours, extensive house plant collections, marathon running outfits and beyond! All in all, our online social experiment was a success, bringing our members a little closer albeit virtually 😊



PANORAMA OF LUPUS CARE in 2020

with prof. Laurent Arnaud



On the 28th we had a session with Prof. Laurent Arnaud, who is a professor of Rheumatology at the Department of rheumatology, University Hospitals of Strasbourg and French National Reference Center for Rare Auto-immune diseases. His main research interests focus around the development and systematic evaluation of biological and immunomodulatory treatments for systemic diseases, with particular interest in the pathogenesis, diagnosis, and treatment of Systemic Lupus Erythematosus and the antiphospholid syndrome.

Prof. Arnaud presented the situation of lupus care today. According to Prof. Arnaud, the most important event in history for autoimmune disease was the discovery of corticosteroids in the 1948, first used at the Mayo Clinic. In the early 1950s 50% of people diagnosed with lupus died within one year. After the discovery of corticosteroids, today, 95% of people diagnosed with lupus live long lives. This is due to many different treatment possibilities, but also to a much great awareness of lupus. But there are still many challenges ahead: there is still too much damage caused by lupus, and Quality of Life for lupus is not as we want it, and even if the life expectancy is greatly improved, it still is not perfect and that should be improved. Prof. Arnaud went through the different risks in lupus and the different treatments and actions available.

HIGHLIGHTS of this session include

- The difficulties in differentiating whether symptoms in a lupus patient are due to lupus damage or due to active disease and how the treatment approach differs when it comes to damage versus flare-ups
- Our very own Lupus Europe Survey – Living with Lupus in 2020 was discussed by Professor Arnaud. Fatigue was identified as being the most common and bothersome manifestation associated with SLE for patients. Possible, multifactorial causes of fatigue in

SLE were discussed as well as possible treatments depending on the underlying cause(s)

- The Holistic Management of SLE was discussed as well, that includes pharmacological treatments, regular monitoring tests that may be needed, attention to potential comorbid conditions such as antiphospholipid syndrome and lifestyle interventions and how all of those can work together to control disease activity, reduce the risk of future flares and prevent damage

to **WATCH**
the session and Q&A

You can still watch this session
on the Lupus Europe Facebook page [here](#)

LUPUS EUROPE Strategies & Projects 2020-2021

Watch this session to find out all about Lupus Europe's exciting strategies and projects for 2020 and 2021 [here](#)

MEET OUR PARTNERS

We had a chance to connect with our fellow organisations from:

- **EPF** (European Patients' Forum) [find out more here](#)
- **FESCA** (Federation of European Scleroderma Associations) [find out more here](#)
- **Sjögren Europe** [find out more here](#)
- **EURORDIS** (European Organisation for Rare Diseases) [find out more here](#)
- **EULAR PARE** (European Alliance of Associations for Rheumatology - People with Arthritis and Rheumatism) [find out more here](#)
- **ERN ReCONNET** (European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases) [find out more here](#)

They had an opportunity to present themselves, introduce themselves to Convention Delegates and we had a workshop on how we can all best collaborate in the future.

GENERAL ASSEMBLY of New LUPUS EUROPE council session

Only for our members. The General Assembly approved the relocation of Lupus Europe to Brussels, we said goodbye to Kirsi Myllys and Annemarie was re-elected to the Board of Directors.

We welcomed the group 3majmy się razem from Poland and the group BOPRMD from Bulgaria as full Members of Lupus Europe.

We also welcomed the group Crvenir Leptir from Croatia as an associate member.

At the first constituting Board meeting after the Convention the following roles were distributed like this: Chair, **Jeanette** Andersen, Vice chair, **Anne** Charlet, Secretary, **Annemarie** Sluijmers, Treasurer, **Elfriede** Wijsma and Director, **Marisa** Costa. The new Board consists of five Directors (formerly trustees), two Co-opted to the Board and three Admin supports. Here is the new Board of Directors of Lupus Europe ASBL.



From top left corner to bottom right: **Annemarie** Sluijmers (Secretary), **Jeanette** Andersen (Chair), **Klaudia** Kępa (Co-opted), **Anne** Charlet (Vice-Chair), **Marisa** Costa (Director), **Amy** Somers (Admin Support), **Cassandra** Alexis (Co-opted), **Elfriede** Wijsma (Treasurer) and **Zoe** Karakikla-Mitsakou (Admin Support). Unfortunately, **Alain** Cornet (General Secretary) is missing on this screenshot.

LUPUS SKIN & AESTHETIC Care

with Dr. Meelad Habib



Dr. Meelad Habib about Skin and aesthetic care. Dr Meelad Habib, a young very involved dermatologist, talked about the different presentations of skin with lupus.

He explained the three types of skin lupus: acute, subacute and chronic chilblain profundus. He pointed out the characteristics of skin Lupus. He showed a special skin lupus case (profundus) he treated to fill up a dimple caused by lupus profundus with own body fat.

He pointed out that this, or any other cosmetic surgery only can be done, when the patient has an inactive lupus, and the treatment is done by a multidisciplinary team. He also showed the advice for protection. After the presentation Dr. Habib answered all questions, some of which he couldn't answer because more study should be done, he suggested some of the questioners to ask the Dermatologist in her/his own hospital.

HIGHLIGHTS of this session include

- Cutaneous skin lupus can evolve into systemic lupus erythematosus
- There are three different types of skin lupus, not just one
- Treatment of skin lupus should be started by a medical specialist such as a rheumatologist or a dermatologist
- Tips or how people with skin lupus or SLE can protect their skin from sunlight and UV radiation. Those tips include applying sunscreen every 1.5-2 hours, using sunblocks, using a hat or sun-protective clothing depending on the degree of sun sensitivity, making use of physical barriers such as umbrellas, parasols and sunglasses

to **WATCH**
the session and Q&A

You can still watch this session
on the Lupus Europe Facebook page [here](#)

LUPUS RESEARCH CLINICAL TRIALS and why so many fail

with Prof. Richard Furie



One of the great things about organising an event online is to be able to include the whole world in your planning and finally managing to get an American “big name” in Lupus research to speak on a European forum. And he was Professor Richard Furie, the Chief of the Division of Rheumatology in Northwell Health, New York. For the past 20 years he has served on many committees of the American College of Rheumatology, but he has played an instrumental role in drug development and clinical trial design in SLE and lupus nephritis.

His talk was about Lupus Clinical trials and why so many fail. First of all, he emphasized the challenge of finding one medication to treat all of lupus that is one of the most heterogeneous disease. He laid out scientific rationale of some of the current trials.

He talked about trials targeting interferons, targeting b-cells, plasma dendritic cells (pDCs), eliminating b-cells, targeting plasma cells and targeting T cells. These were all examples of new development in lupus research.

Furie mentioned voclosporin and as we all know by now, the FDA approved it. Now we’re waiting for EMA to approve it, too. He said that the trials fail no more. Lessons have been learned from the previous failures. We have promising drugs on the way.

- When a trial fails, you never know if the cause is the drug, design, or the designers.
- Lupus activity is overstated (e.g. rash – the different types of rash give different points of activity).
- Background therapy may affect the results.
- Multiple pathways that are active, perhaps we need to target many molecules in the case of lupus.
- Endpoints may not be optimal
- Should we be doing organ-specific studies (skin vs kidney)?

HIGHLIGHTS

of this session include

- There is an incredible clinical heterogeneity in patients with Lupus. People can have a vast array of very different manifestations of the disease. This creates unique challenges for patient prognosis, for the development of new medications and for the design of clinical trials. Lupus patients are like snowflakes, each one is unique
- There have been a number of new therapeutics for lupus over the last twenty years. They include mycophenolate mofetil and belimumab
- Discussion of what the next ten years might bring in terms of new therapeutics. Lots of exciting new developments in terms of lupus research on the horizon.
- Professor Furie also mentioned two new possible medications currently in clinical trials and that he is hopeful we may have two new lupus medications in the next few years, depending on results
- Discussion on why lupus clinical trials so often fail and how the design of clinical trial might be improved
- Professor Furie is optimistic about the future! He believes biomarkers will be identified, making individualised, targeted therapy easier and that this – together with the development and possible approval of new medicines - will lead to better outcomes for patients with lupus

to **WATCH**

the session and Q&A

You can still watch this session

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