Despite these potential pitfalls, we believe that the EULAR/ACR criteria are a relevant step forward in appropriately defining who has SLE, and in teaching doctor and medical students how to approach a patient with possible SLE. The data have clearly demonstrated that ANA negative SLE is uncommon, and ANA are a useful entry criterion or screening parameter in case of suspected SLE. The analysis of interaction has important implications in that it has shown interactions within domains, upholding this concept, but not found significant associations between domains (or items in various domains). The latter in fact is an argument that SLE is indeed a disease, not a syndrome, and that it is the effector arm of the autoantibodies in any given SLE patient that underlies the variability.

Conclusions We will need more knowledge on autoantibodies, not less, and probably more clinical training, but this is more of a chance than a challenge. Above all, it has been remarkably easy to work together in this huge group, over the Atlantic and beyond, and I am deeply grateful for the contribution of so many colleagues. This large team experience of collegiality and friendship will hopefully help the further worldwide collaboration that is necessary for advancing the field.

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**Abstract i6 Figure 1** Delineations of cutaneous diseases. Thomas Bateman, London (1918)

(Systemic Lupus Erythematosus). The modern history of lupus is notably marked by the discovery of lupus cells (LE cells) by Hargraves in 1948, of antinuclear antibodies by Miescher in 1954 and by the recognition of DNA as the main target of ANAs by Seligman in 1957.

Many treatments have been proposed for lupus throughout the ages, including the use of cauterization & caustics (from the middle age to the modern era), radium (1900–1905), and even concentrated sun light & UVs in London in 1905! Quinine was introduced in 1894 while most modern treatments for SLE appeared in the second half of the 20th century: glucocorticoids (1948–1952), quinacrine (1951), cyclophosphamide (1954), hydroxychloroquine (1956), azathioprine (1957) and mycophenolate mofetil (1980s). The end of the 20th century and the beginning of the 21st century are marked by a better understanding of the pathogenesis of the disease and the systematic evaluation of treatments, paving the way for improved diagnosis and better care for lupus patients.

**Abstract i7** PATIENTS EXPECTATIONS, AND WHAT WE (CAN) DO ABOUT IT

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Background Lupus patient’s expectations are no different than everyone else’s: ‘A better life’. But achieving it requires different steps because it entails (1) A prompt diagnosis, (2) Access to effective treatment with low side-effects, (3) Resolving...
fatigue, depression and the social impact of the disease, and (4) Being involved – individually and collectively.  

Methods LUPUS EUROPE is the umbrella organisation that federates, since more than 30 years, national self-help lupus groups around Europe. Through a wide range of initiatives, it seeks to bring alive its vision of ‘a better life for people with lupus in Europe, until we reach a world without lupus’.  

Results Lupus Europe actively works on all drivers of a better life with lupus. This is constant work in progress with multi-party collaboration:  

a. Prompt diagnosis – Awareness events are run locally, but more must be done, particularly for GP’s, ensuring that lupus signals are identified and testing/referral to expert is done much earlier.  

b. Access – Only 54.3% of European patients are satisfied about their lupus care. Patients expect much awaited new treatments, with a focus on corticoid reduction and targeted therapies for those not responding to standards of care. Lupus Europe engages with academics and industry in more than 20 projects to better understand the disease and design better treatments; and with ERN–ReCONNET to bring best available care to all in Europe. The Patient Advisory Network is available to support your projects with significant patient’s added value.  

c. Fatigue, depression and social impact: treating lupus is one thing, but even when lupus is controlled, a significant proportion of patients continue to claim debilitating fatigue, depression, or the inability to participate fully in a social life. Much remains to be understood and resolved. Lupus Europe will conduct a survey ‘living with lupus in 2020’ to measure evolution since our 2010 survey. In the meantime, we are not powerless: (i) Lupus Europe designed an exercise program, endorsed by the ERN to help patients start fight fatigue with exercise, regardless of their current fitness level, and (ii) practical tips based on social psychology and patient experience can help fight depression.  

d. Being involved – Individually: Our patient panel on adherence highlighted that being involved in the decision making (feeling listened to, understanding the disease/treatment, and shifting from ‘YOUR prescriptions to OUR treatment plan’) is key to increase adherence.  

e. Being involved – Collectively: Patients are increasingly ready to be involved in the fight against lupus and to be trained to help. ‘Nothing about us without us’ is not a political motto, but a strong desire to be part of the solution. Our experience shows that involving patients in research is a triple win: win for the project, (funding or process often requires patient involvement), win for the team (new insights and out of the box thinking from collaborating patients), and win for the patient (being involved has a therapeutic effect and hopefully results in a better end product/treatment). Many patients do not know how they can be involved in research close to their homes. When options are explained by a person they trust (#1 is their rheumatologist), a majority is interested in taking part. A key area of work to concentrate on is to train both patients and researchers so that patient involvement is not perceived as an additional burden in an already very full schedule, but a valuable help, even very early in the process.  

Interestingly, interactions with patients repeatedly highlight the precious link established between patients and their lupus specialist. Patients are incredibly thankful to their doctors for their commitment, knowledge and relentless efforts to support them, so often way beyond professional obligations. One can say that one of the patient expectations is also to have a ‘happy rheumatologist’, and there also, we are willing to help.  

Conclusions Unsurprisingly, Patient’s expectations are to have ‘A better life’. Working together, much progress has already been made, and LUPUS EUROPE is committed to keep working on this, together with all partners.  

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