

## 6 PROPOSED INSIGHTS FROM PATIENT'S EXPERIENCE TO FEED YOUR 2024 LUPUS PRACTICES

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**Objective** Provide lupus doctors with concrete insights from patient's experiences that can feed their day to day practices and improve outcomes.

**Methods** Lupus Europe's Patient Advisory Network, Youth group and Board provided qualitative input on patient experiences on a range of topics. Their input was thematically analysed and conclusions drawn.

**Results** Diagnosis - A lupus diagnosis for many patients provided answers and an initial sense of relief. However, for a significant number it triggered fear and anxiety. **Signposting at diagnosis to support groups** would be welcomed and may allay some fears. Doctors sometimes tell patients that their lupus is 'mini' or small when the lupus is 'low severity' medically, perhaps trying to reassure. However, feedback is that this is patronising and minimises the effect lupus has. Only a handful of people felt it would make them feel better. For many, the unpredictable aspect of lupus made such a statement "irrelevant".

Information - Patients would like substantially more information from their doctor, at diagnosis. Some found initial information in support groups or patient organisations, others used books or the internet, which sometimes flagged outdated and worrying information. The use of the internet is a large part of many lupus patients journey, at diagnosis to learn about Lupus, find support groups or seek research and journals, but also when they identify new symptoms or get new medication. Using google for lupus is rarely a good idea! **What would be most helpful is that the doctor directs them to reliable sources of information online and in print, if required (like the lupus100.org site).** To note, Chat GPT is not (yet?) a resource that is used by patients for Lupus information.

Adherence - On adherence, patients said side effects were the biggest issue, followed by mechanical issues, such as size and taste. A pill box was seen as helpful to improve adherence to pharmacological treatments (also to check if you have already taken your medication, a common issue with lupus fog). When asked how doctors could improve adherence, the overwhelming consensus was **explaining exactly why each treatment is needed and the risks of not adhering.**

Hot topics - Pregnancy can be challenging with lupus but often possible. Patients want doctors to tell young women and men that it is possible with proper care. The need to **discuss pregnancy with males** came up repeatedly. On the topic of sex the results were more mixed with 50/50 on wanting, or not, doctors to proactively raise the subject. Also of interest, **alcohol, smoking and drug use** are topics that patients will not spontaneously raise, but would like to discuss with their doctor.

Communication - Around half of respondents have a lupus doctor who operates in a multi-disciplinary team but a common theme was poor communication between different specialists. A theme that came out very strongly was that **patients want to feel listened to** and that lab results are only part of the picture. They want doctors to consider how Lupus is affecting their function, quality of life and their mental health. Which specific elements doctors extract from this is up to

them, but **ensuring the patient feels heard** brings positive impacts and credibility.

Holistic approach - Diagnosis can be a relief but can also cause anxiety, as can a life with Lupus, so a **discussion around mental health** would be welcomed by many. Patients feel that doctors tend to place emphasis on clinical and lab findings when these are not always the most important things to patients. They seek a **holistic approach where quality of life and function are considered** and want doctors to listen to what matters most to them. Empathy and a non-judgemental approach are highly valued.

**Conclusion** In day to day practice, small things can make a big difference. Signposting patients to support groups or proper information; Expressing that you have heard them; Bringing up for possible discussion the hot topics of Pregnancy (also with men), alcohol, smoking and drugs; and Addressing the issue of mental health in a more holistic approach are proposed insights for improved Patient-Doctor collaboration.

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## WHAT IS STILL UNCLEAR IN LUPUS PREGNANCIES?

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**Objective** Despite the many years efforts of physicians and scientist to improve the outcome of pregnancies in patients with systemic lupus erythematosus (SLE), a recent publication<sup>1</sup> underlines the occurrence of many complications for the mother and the child. Aim of this abstract is to summarize the better strategies to ensure a good maternal and neonatal outcome.

**Methods** The physicians' task should be considered in 3 different scenarios: before, during and after pregnancy. The correct approach and the challenges of these 3 periods will be analyzed.

**Results** Ideally, a patient should start the pregnancy when the diseases is in low disease activity or in stable remission under a treatment safe for the fetal health. This is not always the case because sometimes unwanted pregnancies occur or, in other circumstances, desired pregnancies do not come. In both cases the treating physician will be involved in the solution finding process so it could be of help to know in advance what could be done and prepare sound specific protocols. The pre-conceptional counselling also involves the case specific evaluation of potential risk factors for the future pregnancy. These include the evaluation of lupus phenotype, antibody profile and other biomarkers such as the complement system whose levels are important predictors of fetal outcome even if not linked to clinically important disease activity.<sup>2</sup>

The monitoring of lupus patients during gestation is performed by a multidisciplinary team where gynecologist together with rheumatologists/internists are the main players. It is sometimes difficult to have different specialists at the same time in the same place, so different organizational models of multidisciplinary team have been developed to ensure