

# EULAR Sjögren's syndrome study group: an eSSential way to address the unmet needs of the disease

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In 2017 EULAR created a study group devoted to Sjögren's syndrome (SS), called eSSential (EULAR Sjögren's Syndrome Experimental aNd Translational Investigative Alliance Study Group). The aim of this study group was to promote the sharing of knowledge for SS, define biomarkers, facilitate synergistic-collaborative research initiatives in Europe and address the unmet needs of the disease. Over the last 2-3 years, the study group presented very interesting and helpful results including the standardisation of labial salivary gland biopsies (1), the Foreum grant for the stratification of SS patients (2) and results from the ultrasound sub-study group, aiming to validate the ultrasound of salivary glands as a diagnostic tool for the disease (3). During these years the study group was led by F. Barone, T. Radstake and F. Ng who have to be congratulated for the good work done.

eSSential is now passing into a new era, where the aims have virtually not changed, but they have been specified as follows:

- Develop a core dataset for SS;
- Definition of clinical phenotypes of Sjögren's syndrome, based on large integrated cohorts;
- Define universally accepted prediction models for lymphomagenesis;
- Develop "standard operation procedures" for the collection and storage of biological samples;
- Develop standardisation measurements to use salivary gland biopsies as outcome in clinical trials;
- Validation of old and discovery of new biomarkers (4);
- Application of system biology approaches in the clinical setting.
- Investigate the use of ultrasounds as tools of clinical activity and outcome (5).

Our primary focus is to communicate research initiatives from all over Europe that have been granted for SS. eSSential functions as a "EULAR umbrella" that includes the following projects:

i) HarmonicSS, which has as a major objective the harmonisation of SS patients and through this to address the unmet needs of the disease (6).

ii) NECESSITY, a European project (IMI: innovative medicines initiative) to define new clinical useful endpoints in an interventional trial based on that stratification of patients with primary Sjögren's syndrome.

iii) PRECISESADS, that attempts to perform, using high-throughput OMICs data (genetic, epigenomic, transcriptomic, combined with flow cytometric data, multiplexed cytokines, as well as classical serology), an integrated bioinformatics analysis to identify signatures that will provide clinically and immunopathologically relevant information, with the aim of reclassifying all patients affected by SS into clusters of molecular entities, whatever their disease activity or treatment in view of precision medicine strategies (7).

iv) to define new composite indexes for the outcome of patients, as for example is the Composite of Relevant Endpoints for Sjögren's Syndrome (CRESS), based on the expert opinion and analysis of trial data (8).

v) EULAR ultrasound pSS Study Group for the development of a new scoring system for salivary glands, useful for the follow-up in clinical trials.

All these research endeavours have recently been presented during the EULAR 2020 congress.

We feel that among the priorities of eSSential it is also to find the proper ways for interaction and complementary actions that will facilitate the maximal effect of research for SS in Europe. To this

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end, in the recent e-EULAR Congress, eSSential presented work that has been done in the context of HarmonicSS, regarding the aspect of the disease from the primary care point of view. This is particularly important, since many SS patients are examined by primary care providers and not specialised centres, thus providing new insights for the public health policy that should be followed in SS. Another significant action was the presence and active participation of patients' advocacies with SS and the initiatives that have been started. The last two years under the leadership of EULAR PARE, which is a partner of HarmonicSS, a patients' association with SS beyond the national levels (the SS-Europe) has been created for the first time. This initiative will give us a more concise view of the social, economic and scientific burden of the disease from the patient's perspective. In the new decade eSSential has the main mission to bridge the activities for

SS at multiple levels including clinical, social and public health policy. Our goal is to efficiently collaborate not only with the individual research groups of Europe, but also to create stable bonds with activities in other continents, such as the SS study group of the American College of Rheumatology (ACR) and others. We trust that these efforts will be embraced and augmented by all physicians, researchers and people involved in the disease.

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