

University of Groningen

EULAR Sjogren's syndrome study group

Tzioufas, A. G.; Bootsma, H.; Pers, J. O.

Published in:
Clinical and Experimental Rheumatology

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2021

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Tzioufas, A. G., Bootsma, H., & Pers, J. O. (2021). EULAR Sjogren's syndrome study group: an eSSential way to address the unmet needs of the disease. *Clinical and Experimental Rheumatology*, 38(4), S23-S24. <https://www.clinexprheumatol.org/abstract.asp?a=16014>

Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

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

A.G. Tzioufas¹, H. Bootsma², J.O. Pers³

¹Department of Pathophysiology, School of Medicine, National and Kapodistrian University of Athens, Greece;

²Department of Rheumatology and Clinical Immunology, University Medical Centre Groningen, University of Groningen, The Netherlands;

³LBAI, U1227, University of Brest, INSERM, CHU de Brest, France.

Athanasios G. Tzioufas, MD, PhD
Hendrika Bootsma, MD, PhD
Jacques-Olivier Pers, MD, PhD

Please address correspondence to:
Athanasios G. Tzioufas,
Department of Pathophysiology,
School of Medicine,
National and Kapodistrian
University of Athens,
Mikras Asias Str. 75,
11527 Athens, Greece.
E-mail: agtzi@med.uoa.gr

Received on June 19, 2020 and accepted
on June 23, 2020.

Clin Exp Rheumatol 2020; 38 (Suppl. 126):
S23-S24.

© Copyright CLINICAL AND
EXPERIMENTAL RHEUMATOLOGY 2020.

Key words: primary Sjögren's
syndrome, biomarkers

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

Competing interests: none declared.

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.

References

1. FISHER BA, JONSSON R, DANIELS T *et al.*: Standardization of labial salivary gland histopathology in clinical trials in primary Sjögren's syndrome; Sjögren's histopathology workshop group (appendix) from ESSENTIAL (EULAR Sjögren's syndrome study group). *Ann Rheum Dis* 2017; 76: 1161-8.
2. NG W-F: SP0173 Stratifying primary Sjögren's syndrome patients. *Ann Rheum Dis* 2018; 77 (Suppl. 2): 46.
3. MOSSEL E, DELLI K, VAN NIMWEGEN JF *et al.*: Ultrasonography of major salivary glands compared with parotid and labial gland biopsy and classification criteria in patients with clinically suspected primary Sjögren's syndrome. *Ann Rheum Dis* 2017; 76: 1883-9.
4. TZIOUFAS AG, GOULES A: The necessity of novel biomarkers in primary Sjögren's syndrome. *Clin Exp Rheumatol* 2019; 37 (Suppl. 118): S16-8.
5. INANC N, ŞAHINKAYA Y, MUMCU G *et al.*: Evaluation of salivary gland ultrasonography in primary Sjögren's syndrome: does it reflect clinical activity and outcome of the disease? *Clin Exp Rheumatol* 2019; 37 (Suppl. 118): S140-5.
6. GOULES AV, EXARCHOS TP, PEZOULAS VC *et al.*: Sjögren's syndrome towards precision medicine: the challenge of harmonisation and integration of cohorts. *Clin Exp Rheumatol* 2019; 37 (Suppl. 118): S175-84.
7. BARTUREN G, BABAEI S, CATALÀ-MOLL F *et al.*: Integrative analysis reveals a molecular stratification of systemic autoimmune diseases. integrative analysis reveals a molecular stratification of systemic autoimmune diseases. *medRxiv* 2020.02.21.
8. ARENDS S, VAN NIMWEGEN JF, VERSTAPPEN GM *et al.*: Composite of Relevant Endpoints for Sjögren's Syndrome (CRESS) [abstract]. *Ann Rheum Dis* 2020; 79 (Suppl. 1): 1026-7.