

EULAR NEWS

Systemic sclerosis in Europe: first report from the EULAR Scleroderma Trials And Research (EUSTAR) group database

Under the auspices of the EULAR Standing Committee for International clinical Studies Including therapeutic Trials (ESCIIT), the EULAR Scleroderma Trials And Research (EUSTAR) group was officially founded in June 2004 during the Berlin EULAR congress. This was the culmination of 18 months' intense activity by many people across Europe, and a summary is available on the website (<http://www.EUSTAR.org>). The logo (fig 1) features a star from a painting by Paul Klee, who himself succumbed to this dreadful disease.

An integral part of the EUSTAR mission was the development of a Minimal Essential Data Set, called MEDS. This consists of a simple two page form containing domains relating to basic demographics, disease subsets, autoantibodies, disease activity, disease duration, and organ involvement, including modified Rodnan skin score, body weight, and carbon monoxide transfer factor (TLCO, % of predicted). Also included are yearly follow ups and details of deaths, and the data are entered into an interrelational database located in Florence.

As of December 2004, 1900 patients have been entered into the database from 76 centres: 646 diffuse cutaneous (dc)SSc (83% female), 1059 limited cutaneous (lc)SSc (90% female), and 195 classified as "other". Median disease duration (from appearance of the first non-Raynaud's symptom) for dcSSc was 65 months and for lcSSc

98 months. In dcSSc the median modified Rodman skin score was 18 (0–51) and in lcSSc 7 (0–32). The autoantibody profiles were for dcSSc—Scl-70 63%, anti-centromere 6%, and for lcSSc—Scl-70 23% and anticentromere 53%.

As expected more pulmonary fibrosis was seen in the dcSSc group (53% *v* 30%) but pulmonary artery hypertension was almost equal (19% *v* 17%).

Of the 11 deaths reported, eight were in the dcSSc group and all due to disease, whereas the three deaths in the lcSSc group were due to treatment and "other".

The aim of the MEDS is to obtain extensive basic semiquantitative data on this rare disease throughout Europe from diverse specialty groups to avoid selection bias. In addition, with careful follow up, it is hoped that early prognostic markers of outcome will emerge to direct timely appropriate treatment in the future.

Already the first year of data defines and "tracks" different subgroups of SSc, which are then available for more focused studies between interested groups. Centres contributing more than 20 patients are automatically included as co-authors in any publications arising from the MEDS, and clear and fair guidelines for exploiting the MEDS exist.

Clearly, as with all new enterprises data quality improves with time. A modified Rodnan skin score of zero for dcSSc needs explanation, and a continuous data cleaning and query process

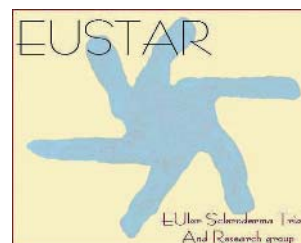


Figure 1 EUSTAR logo.

has been set up. In addition, EUSTAR courses have taken place and it is planned to standardise SSc assessment, including completion of the MEDS forms.

The whole EUSTAR effort, including the MEDS, would not have been possible without a generous grant from EULAR. It is now the responsibility of the EUSTAR management and the MEDS committee to further justify this support. All colleagues who care for patients with SSc are invited to download and complete the two sided MEDS form from the website, which results automatically in the allocation of a unique centre number and EUSTAR membership. Welcome.

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