Pediatric Rheumatology

Poster presentation

The prospective juvenile systemic sclerosis inceptions cohort – http://www.juvenile-scleroderma.com

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Introduction

Juvenile systemic sclerosis (jSSc) is a rare disease. We developed a prospective assessment protocol for disease involvement manifestations and progression of jSSc.

Objectives

To learn about the evolution of organ involvement, the reliability of proposed assessment tools to measure change in organ involvement, and the outcome of patients in an early jSSc cohort.

Methods

Early jSSc patients, enrolled within 18 months after the first non-Raynaud symptom of the disease, will be followed over 36 months using a standardized assessment protocol. No specific therapy will be suggested. An Internet platform was created to make the project accessible: http://www.juvenile-scleroderma.com. Interested colleagues can request the protocol, assessment tools, and a model consent form to apply for local IRB approval. After they receive local IRB approval, they will receive an access code to the internal side of the homepage, where the detailed protocol of the project and the assessment sheets for the visits in PDF format are available. Data entry of the patients is de-identified. The data will be summarized every 6 to 12 months and presented at rheumatology meetings. The principal investigator of each center will be listed as co-author according to the number of enrolled patients. Every 12 months the assessment tools will be evaluated, with the help of a biostatistician, according the OMERACT criteria.

Conclusion

This project will represent the first prospectively followed cohort of jSSc patients, and will enable us to learn about evolution disease and about the reliability of the proposed assessment tools.