

JUVENILE SCLERODERMA



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Any chronic disease is a major problem for those affected. If this disease begins before reaching adulthood, this problem will be greatly increased by all the repercussions it may have on the maturation and development process at a stage when the human being undergoes marked physical, psychological, emotional and cultural changes that are part of his path to becoming an adult integrated into human society.

Scleroderma is a relatively rare disease, but it can have significant repercussions on the health of affected patients, particularly if it is not quickly diagnosed and the most appropriate measures and treatments are not put in place to prevent the progression of the disease and the involvement of internal organs, which can lead to changes in the health and quality of life of affected patients.

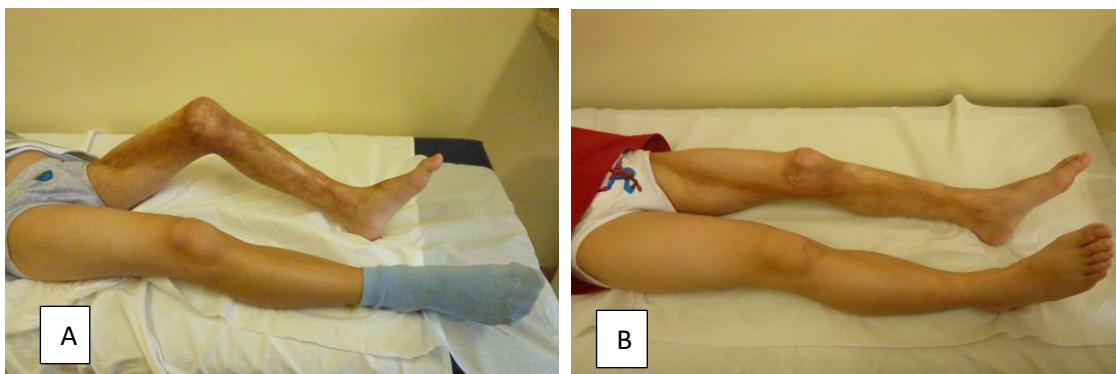


Figure 1 - Linear Scleroderma of the left lower limb: (A) Before and after (B) appropriate medical and rehabilitation treatment.

However, in childhood, most Scleroderma cases are localized disease cases - of which linear Scleroderma, "en-coup-de-sabre" Scleroderma, Parry-Romberg disease and Morphea are the most common. These localized diseases have a very favourable long-term functional prognosis compared to the systemic form of Scleroderma, that is much more common in adulthood. Regarding systemic Scleroderma, only about 3% of cases start under the age of 18.

Whether the Scleroderma is localized or systemic, what must be retained as very important is that:

- 1 - Diagnosis should be made as soon as possible after the onset of symptoms. For this, early referral to a Pediatric Rheumatology appointment is fundamental.
- 2 - The disease can be adequately treated and treatments are more effective if there are no established internal organ and/or skin lesions.

3 - The disease is only an aspect of the person, **"IT IS NOT THE PERSON!"**

These patients should therefore be encouraged and motivated to follow all their dreams and passions, some of which may be difficult to fulfil, as happens to all other "normal" people, healthy or not, who may not always succeed in fulfilling and implementing all their dreams. This should not be a reason for discouragement and frustration, but should be understood as a characteristic of human beings who project the future without being able to master all the variables that influence it...

Paul Klee, who also suffered from Scleroderma, did not give up his artistic and academic career at the Bauhaus, and pursued all his dreams and creative activity until the end of his life.



Figure 2 - Parry Romberg's disease - Form of Localized Scleroderma that causes atrophy of the soft tissues of half the face and frontal region. The good evolution over 8 years can be seen with the treatment carried out.