How can I participate in the DeSScipher project?

Every health care center can include people with systemic sclerosis in the DeSScipher project. **Contact details** of currently participating centers can be found **on our homepage**. If your center is not already listed, and you want to participate, **please ask your physician**, if your health care center wants to become a contributing partner to DeSScipher.

As **FESCA** is a founding partner of DeSScipher, the national FESCA representative or your **local systemic sclerosis association** may provide you with some additional information. Of course, you can also find more information or directly contact us by visiting **DeSScipher´s project homepage www.desscipher.eu**.

We are grateful to every people with systemic sclerosis participating in the DeSScipher project, helping to make DeSScipher a success in finding the optimal management of systemic sclerosis.

This project is not about "science on you", but wants to provide "science for you" to improve the quality of life for people with systemic sclerosis.

Kind regards
The DeSScipher research team

DeSScipher partner consortium:

DeSScipher –„To decipher the optimal management of Systemic Sclerosis"

Für weitere Informationen besuchen Sie bitte:
www.desscipher.eu

DeSScipher

Information brochure for people with systemic sclerosis

DeSScipher - „To decipher the optimal management of systemic sclerosis"

The 1st EU-funded international observational research project on systemic sclerosis

Dear people with systemic sclerosis,

on April 1st 2013 the observational trials of the international EU-funded research project “DeSScipher” have started. It is in fact currently the **largest research project ever** for systemic sclerosis, we kindly ask you for your participation.

What is DeSScipher about?

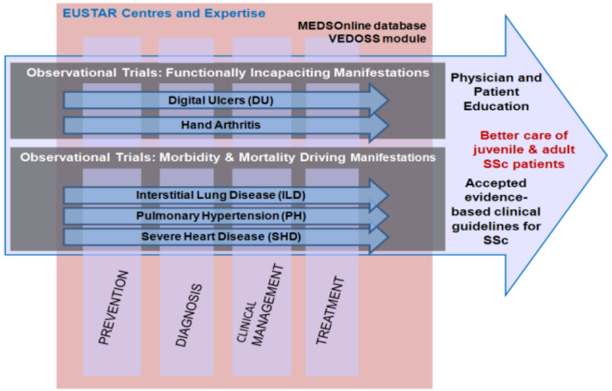
DeSScipher is the acronym for **”to decipher the optimal management of systemic sclerosis”**. The project mainly consists of five observational, non-interventional studies, conducted over a period of at least 3 years. The aim of this project is to improve the treatment strategies for systemic sclerosis, and **thus to improve your quality of everyday life** with your disease in the future. Moreover, DeSScipher aims to improve the education of physicians, and to achieve a **better care** for people with systemic sclerosis by the development of accepted evidence-based clinical guidelines.

What does “observational” mean?

Contrary to an interventional study, where the treatment of patients is altered, e.g. by adding a novel drug to your list of medications, **an observational study is restricted to recording** the effects of the medications that your physician is prescribing you. The patient´s disease will only be **monitored very closely** to explore, whether an existing treatment may be beneficial or not. The patient stays on his/her medication, as prescribed by his/her physician, and this medication is only changed, if the physician sees a medical need to do so, and **medication won´t be changed** because of the participation in an observational study.

The five observational trials (OTs)

The DeSScipher project consists of **five observational trials**, which are designed to cover the different evolutionary phases of the disease, from early manifestations such as digital ulcers and hand arthritis to later manifestations such as interstitial lung disease, pulmonary hypertension and heart disease.



OT 1 - Prevention and treatment of digital ulcers

Digital ulcers are a frequent problem and the cause of functional impairment and substantial loss of quality of life in many people with systemic sclerosis. That is why this observational trial aims to identify the **best treatment strategy** for the prevention and healing of digital ulcers.

OT 2 - Improvement of hand dysfunction by arthritis

Besides digital ulcers, **arthritis** may also cause deterioration of hand function in people with systemic sclerosis. Thus, this study aims to identify the **incidence** of arthritis, **potential predictors** for its onset, and the **best treatment strategy** of arthritis.

OT 3 - Prevention and treatment of interstitial lung disease (lung fibrosis)

Lung fibrosis and resulting shortness of breath is one of the most important organ involvements of systemic sclerosis that reduces quality of life and limits daily activities. This observational trial aims to identify the current state of clinical practice for the **prevention and treatment of lung fibrosis**, its effect on lung function and disease progression and **potential predictors for the response to therapy**.

OT 4 – Development and prevention of pulmonary hypertension

Several new treatment options have been developed within the last years and have increased the quality of life for people with systemic sclerosis affected by pulmonary hypertension. Unfortunately, **pulmonary hypertension** is still a severe complication of systemic sclerosis. For this reason, this study focuses on the **time before the onset** of pulmonary hypertension and looks at whether there are any medications that can **prevent or delay the development** of pulmonary hypertension.

OT 5 – Development and prevention of severe heart disease

Cardiac involvement is **often a silent disease manifestation** that is without discomfort in up to three out of four people with systemic sclerosis. However, in some cases it can progress to a more severe level. This trial **focuses on the early stage of heart disease** and the potential of different medications **to prevent cardiac events** in people with systemic sclerosis.