DeSScipher news for people with SSc – 03/2014

Almost a year ago, the largest research project ever for systemic sclerosis. the observational trials of the international EU-funded research project "DeSScipher" began.

What is the DeSScipher project?

DeSScipher is the **1st international EC-funded research project**, and currently also the largest project, on the rare disease systemic sclerosis (SSc). DeSScipher aims **to decipher the optimal management of systemic sclerosis.** The goals of this project are to improve the treatment strategies for people with systemic sclerosis, and thus to help affected patients to get more quality of life. The projects comprises **five observational, non-interventional studies** which started in April 2013 and have been designed to cover different evolution phases of the disease from early, functionally relevant manifestations such as **digital ulcers** and **hand arthritis** to later, more severe organ manifestations such as **interstitial lung disease**, **pulmonary hypertension** and **severe heart disease**. Moreover, DeSScipher aims to improve the **education** of people with systemic sclerosis and physicians, and ultimately to achieve a **better care for patients** by the development of accepted evidence-based clinical **guidelines**.

The activities of FESCA within the DeSScipher project

FESCA aisbl. is a full partner of the DeSScipher project and deeply involved since the very beginning of the five observational trials. The main task of FESCA is to actively disseminate the research project in Europe and in its member countries.

The first appearance was at EULAR Madrid, June 2013 where at FESCA own stand DeSscipher information materials were placed. The launch or kick-off of the project at national levels was on World Scleroderma Day, on the 29th June 2013. Most of the countries who organised conferences asked a specialist or FESCA representative to talk about the project (The Netherlands, France, Spain, Denmark, Hungary, Switzerland).

In some countries the Project was introduced by successful press conference (Cyprus, Finnland).

Cyprus – press conference

France - congress materials

The Netherlands - congress

France – Prof. Yannik Allanore lecture

In Croatia activites were organised on this Day around 'Get the Gloves on' campaign where DeSsciher Project connected to it („presentations of the project through posters and leaflets, as well as interviews with physicians resulted in the inclusion of physicians from four clinical centers in this long-term observational project. Patients were also informed about the project and are continuously encouraged to cooperate with doctors on this project."-by Sanja Roskar, HUOS). In Hungary the project materials were distributed in the project founder clinic, Pecs.
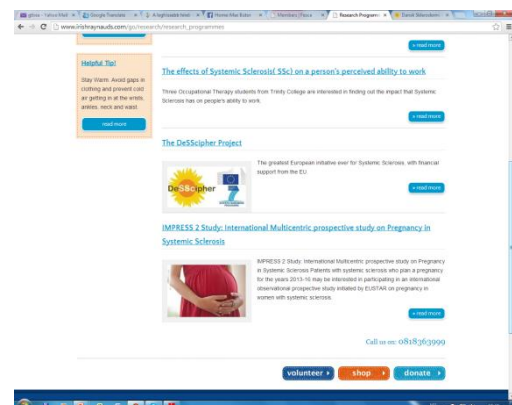

Pictures at the corridor of the Pecs clinic

WEBSITE: Almost all members released the project news in their own newsletter of their associations and some on their websites.

The Ireland published advertistment in the Irish Medical News.

Spain, Ireland, Croatia, Romania achieved serious interest with clinics to contribute to the study.

FESCA keeps including news into its regular Newsletter and Facebook.

The objective of the dissemination by FESCA is to increase awareness of the disease and the DeSscipher Project and finally but not least to let patients know about this research opportunity which is NOT invasive, no new drugs are used but OBSERVATIONAL only.

What has been achieved within the last year?

So far, **812 SSc patients have already been screened** for the 5 observational trials and **523 SSc patients were enrolled** because they fulfilled the inclusion criteria of at least one trial. However, DeSScipher aims to recruit **up to 4000 SSc patients in total**. Thus, there is still a long way to go. Initially, the project was founded by 10 EUSTAR centers, but within the last year other EUSTAR centers joined the DeSScipher project. If you want to participate in the project, currently **EUSTAR centers in the following countries contribute to the project:** Croatia (Zagreb), France (Lille, Paris), Germany (Bad Bramsted, Bad Nauheim, Berlin, Frankfurt), Hungary (Pécs), Italy (Florence, Naples), Romania (Bucharest, Iasi), Switzerland

(Basel, Zurich), United Kingdom (Leeds, London, Salford/Manchester). Unfortunately, centers in some large European countries like Austria, Belgium, Czech Republic, Greece, Ireland, The Netherlands, Polen, Portugal, Spain etc. are missing. It is a pity, in particular because of the large effort of patient organizations e.g. in Ireland and Spain. But DeSScipher still aims to grow: **every EUSTAR center and all other centers dedicated to SSc patient care can become contributing centers.** Currently, several other centers are obtaining ethics approval for DeSScipher, e.g. in Cologne, Erlangen, and Wuppertal (Germany), Milan (Italy), Chicago and Michigan (USA). And we hope, that more centers will join the project soon.

I want to participate but my patient care center is not listed. What can I do?

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. They are very welcome to participate! However, even if your patient care center is not a contributing partner of the project, you still can help FESCA and the DeSScipher consortium to disseminate the project: we are searching for volunteers who help to translate the DeSScipher project webpage into other European languages in order to spread the knowledge on SSc and raise awareness about the needs of people with SSc.

More information about the DeSScipher project

For more information, please visit the homepage of FESCA (www.fesca-scleroderma.eu) or the website of your national association and the DeSScipher project (www.desscipher.eu).