



**ScreenPro FH**

Screening Project for Familial  
Hypercholesterolemia  
in Central, Southern  
and Eastern Europe

**PROJECT REPORT 2017**





# ScreenPro FH 2017 Report

## Executive summary

The ScreenPro FH Project started in 2014/2015. Based on the Czech MedPed experience the project was established for screening, diagnosis and treatment of FH patients in the region of Central, Eastern and Southern Europe.

We started with 8 countries, now we are 20.

We started with 70 centers, now we are 181 (other 40 in development).

We started with 7500 patients in the local databases, now, they are 23 191.

We started cooperation with patient's organization in 8 countries (2017).

We focus on education, screening and care of FH patients. Nowadays we are on the way from description of the situation to improvement in the treatment.

## The story of ScreenPro FH

### We started with identification of „Country Leader“

At the first Country Leaders meeting (PEDIM 2014 in Prague) we educated them, how the screening program should work in everyday clinical practice.

Leaders were also informed about FH criteria (clinical criteria, not genetic testing is necessary for confirmation). They've started to build centers and in some countries even a networks.

**At the meetings of country leaders**, they provide information concerning the **situation in the country** (number of centers, cooperating doctors, number of patients in the local database, activities in the country) – you will see some „country data“ during our meeting in Prague

**The development of the project is continuously monitored**

## Education and practical support for doctors

When the **basic structure** was established, at least **national center** and several **other regional centers** started to build the network. At this time we started with logistic and educational support of countries.

Countries are provided with **information** on the **web** pages, and also they are offered with **educational materials** to download and translate to regional languages e.g.:

“Information for patient with FH“, “Information for relatives of FH patient“ and also an educational brochure for patients were provided and distributed.

**Support for doctors** was prepared: Card of FH patients for continuous follow up, and medical records, Informed consent are very useful tools.

**FH book** was translated into 5 languages.

**4 papers** concerning the project were published on behalf of ScreenPro FH.



## Description of the situation

The situation in individual countries was monitored and national leaders have provided us with description of the situation at the project beginning and nowadays.

We started with 8 countries, now we are 20.

We started with 70 centers, now we are 181 (other 40 in development).

We started with 7500 patients in the local databases, now they are 23 191.

Patients in the database have to fill-out criteria of FH. (Dutch Lipid Clinics). A standard “set” of **obligatory biochemical measures** for all centers was distributed as a guideline for the future comparison of results and for possible unification of data. For more specialized and developed countries and centers we recommended also some optional parameters to be measured.

Availability of pharmacological treatment in different countries was also described by country leaders, as well as availability of LDL-apheresis.

We have data from individual countries and we are able to demonstrate them at the meeting.

In 2017 we've started cooperation with national **patient organisations**, representatives of patient organisations participated at our meeting in Barcelona during ESC and they presented their experience.

## Activities for 2018:

Continuing effort to increase number of patients in database

Significant improvement of description of patients (see below)

Improvement of the medical care

Improvement of education, both, medical professionals as well as patients

Cooperation with patient organisations

## Our future plans

### Description of patients

- Lipids: LDL levels, total cholesterol, Lp/a/ if available, genetic testing /availability, it is an optional parameter/
- Targets (how many patients reach LDLC goal etc)
- What treatment is used?
- What are possibilities of treatment in individual countries
- CVD in our patients
- Other comorbidities

### Increase number of patients

- In all countries – better education
- Development of network
- Support from the center

### Better description and data collection

- Unified database?
- Countries do not agree to send data to ANY central international database without very strict regulation of handling, authorship, etc.



## Continuous cooperation

- Meeting of leaders and/or active leaders of regional centers are necessary
  - Central, unified proposal for activities
  - Web, electronic possibility of cooperation, education
- Presentation of results at Lipid Academy in Vienna May 2018
- Presentation of results at Prague European Days of Internal Medicine June 2018
- Presentation of the project at international meetings (ISA Toronto, May 2018 – we will have 2 hours session devoting FH and our project)
- Cooperation with patient organizations.

Please find attached presentation with project development summary and a short version of “FH questionnaire” with the “KIT” of obligatory measures for all ScreenPro FH centers.



## ScreenPro FH

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