



ScreenPro FH Project Meeting Minutes

Hotel Quirinale - Via Nazionale 7, Rome, Sala Mascagni

August 29th, 2016 Rome – ESC Congress

List of attendance

Chair: R. Ceska (Czech Republic)

Staff: T. Aleksicova (Czech Republic), L. Votavova (Czech Republic)

Country Representatives:

Bosnia and Herzegovina: B. Pojskic

Greece: A. Tselepis

Kyrgyzstan: E. M. Mirrakhimov

Latvia: G. Latkovskis

Russia: M. V. Ezhov

Russia: A. V. Susekov

Slovakia: K. Raslova

Slovakia: B. Vohnout

Ukraine: E. Mitchenko

Uzbekistan: A. Shek

Welcome and introduction

ScreenPro FH Project is represented by 18 member countries – Bosnia and Herzegovina, Bulgaria, Croatia, Czech Republic, Greece, Hungary, Kyrgyzstan, Latvia, Lithuania, Poland, Romania, Russia, Serbia, Slovakia, Slovenia, Turkey, Ukraine, Uzbekistan

Updates from last meeting

- Web page (www.screenprofh.com)
 - Update of the current situation in member countries – we would like to ask all ScreenPro FH Project Leaders to send us updates from their counties regularly
 - Educational materials – there is going to be a new list “Education materials” where you can find some basic materials for everyday practice translated into English language (Informed consent, Letter for relatives, Information for patients, Questionnaire, Questionnaire for GPs, FH patient card, etc.)
- FH Book – actually translated into 6 languages
 - All ScreenPro FH Project Leaders were informed about the possibility to translate the book in their national languages (National Leaders could add description of the situation in their countries and become a co-author of the book)
- IAS/Pfizer IGLC Grant Request: Lipid Management in High-Risk Patients
 - ScreenPro FH Project is among 13 proposals who have been recommended to receive financial support
 - The financial resources are very limited, but they could cover ScreenPro FH Project Leaders travel expenses and development of selected educational materials
- ScreenPro FH Certificate – all ScreenPro FH Project Leader received certificates “The National Centre of the ScreenPro FH Project”



Where we are now – it's time to be practical

- After a several ScreenPro FH Project Member meetings we are now focusing on practical part of the project. We would like to help you and your centres to increase awareness of FH in member countries development of educational materials for practitioners and patients (Informed consent, Information for patients, questionnaires, etc.).
- We are going to translate FH patient card that is important both for patients and physicians. The advantage is that doctors could see patients' previous treatments, find an information about the cholesterol levels and it can also raise awareness among patients of their health conditions.
- Another important material is a guideline how to establish a lipid clinic/centre – what is necessary for a good care of patients with FH. We would like to ask all ScreenPro FH Project Leaders to send us updated reports from their countries at the regular basis (even it's a small network) it is important for local as well for international cooperation. We would also like you to send us the list (with contact) of doctors cooperating with you at your national centres.

Cooperation with international initiatives

- We have a good cooperation with 10 Countries Study (long term experience with raising awareness and education in Australia and Asian countries) and with EAS FHSC initiative.
- FHSC is organizing the EAS CEE FH Meeting that is being held November 25 – 27, 2016 in Warsaw. ScreenPro FH Project is participating at this event.

Future activities - education & awareness

- Educational materials developing (more about educational materials above) – we informed all ScreenPro FH Project Leaders that they could send us their national educational materials that could be easy translated into English and shared among our project countries.
- Pilot project "Survey research" (questionnaires for GPs and physicians) - awareness of FH in general population is zero, but awareness of FH among GPs is also very low. This is the reason why we are going to develop questionnaires for general population and GPs as a pilot project (cooperation with Gerald Watts and his project 10 Countries Study). The aim of the pilot project is to analyse situation in countries via survey research before and after ScreenPro FH Project educational activities. We are going to send you more information via email, but you can also download questionnaires at the website www.screenprofh.com.
- ScreenPro FH Project unified seminar slide kit – for local/international seminars. We would like to complete it before next meeting at ESC congress in Barcelona. All ScreenPro FH Project Leaders can use this slide kit at their local/regional meetings.
- Future development of the ScreenPro FH Project also depends on PR – we should be more visible as we did a significant piece of work, so now it's the right time to start with publication of our results. Publications should be oriented above all on:
 1. Description of the project
 2. Results from countries
- We would greatly appreciate if anybody could be a main author and corresponding author. We are going to help you and prepare some manuscript draft translated into English and send it to all ScreenPro FH Project Leaders. Please let us know who will be interested in publications. We should publish at least 2 articles in very short future. We can combine data (summarized data without sharing concrete data from countries, each country is only owner of the data) and use description of the project that is already done. Publications could help to promote our project as well as ScreenPro FH Project Leaders role at the national and international level.



Future events

- **EAS-FHSC Central & Eastern European Symposium on FH 2016**
November 25 - 27, 2016 Warsaw
- **The 2nd Prague European Days of Internal Medicine (PEDIM) 2016**
December 1 - 2, 2016 Prague
ScreenPro FH Workshop, ScreenPro FH Project National Leaders Meeting
- **85th EAS Congress 2017**
April 23 - 26, 2016 Prague
ScreenPro FH Workshop, ScreenPro FH Project National Leaders Meeting
- **ESC Congress 2017**
August 26 – 30, 2017, Barcelona
ScreenPro FH Project National Leaders Meeting
- **International Symposium on Atherosclerosis 2018**
June 9 – 15, 2018, Toronto
Satellite meeting and workshop (presentation of ScreenPro FH Project results),
ScreenPro FH Project National Leaders Meeting

Reports from countries

Bosnia and Herzegovina

(Country Leader: Prof. B. Pojskic)

- The population of BiH is around 3,8 million
- National centre - Cantonal hospital Zenica
- Cooperating physicians: Dr. Ena Stimjanin, Dr. Lamija Pojskic, Dr. Harun Selimovic
- Physicians are working on project on a voluntary basis (not involved in the health care system)
- Database - creating Excel spreadsheets and identifying patients with high LDL from the hospital database - identifying FH patients and screening FU in their families
- Collecting all patients with LDL more than 5,5 – identified patients with FH (Dutch criteria)
- Medical Council supports the project granting ECTS leaders and participants in the project
- Activities - educational lectures for GPs, pediatricians, internists, ophthalmologists
- Lecture at the Congress of Cardiologists in BiH on May 2016
- Information about FH at the website of the Association of Cardiologists in BiH - Working Group of Atherosclerosis
- Genetic testing is not used (possible to send results abroad – expensive)
- Lack of doctors and time
- Patient organization doesn't exist
- Ezetimibe is not available in BIH, PCSK9 – not available, only Oddysey study

Latvia

(Country Leader: Prof. G. Latkovskis)

- The population of Latvia is around 2 million
- National centre - Latvian Institute of Cardiology and Regenerative Medicine, Riga
- Cooperating physicians: Dr. Vita Saripo, Dr. Arta Upena-Rozem, Dainus Gilis
- FH registry - initiated in February 2015, run by the Latvian Institute of Cardiology and Regenerative Medicine, University of Latvia
- FH registry is supported by the Latvian State Research Program (no funding from the healthcare budget)



ScreenPro FH Project

- 162 patients in database (in only national centre in Riga)
- 77 patients with confirmed FH, less than 1% of FH patients in country
- Dutch criteria (MedPed and Simon-Broome also registered)
- Improving awareness of FH and collaboration with GPs and cardiologists – lectures for patients, public events
- Reimbursement 50% for statins only, PCSK9 – not reimbursed,

Greece

(Country Leader: Prof. A. Tselepis)

- HELLAS FH REGISTRY “Hellas-FH” – 40 patients in database (expected 2,000 within 1 year)
- National centre: University Hospital of Ioannina + 8 other centres
- Participating centres/cooperating physicians:
 - o University Hospital of Ioannina (Evangelos Liberopoulos)
 - o Onassis Cardiac Surgery Centre (Dr. Genovefa Kolovou)
 - o Papageorgiou General Hospital of Thessaloniki (Vasilios Kotsis)
 - o Hippokratio General Hospital of Thessaloniki (Vasilios Athyros)
 - o Hippokratio General Hospital of Athens (Dr. Ioannis Skoumas)
 - o University Hospital of Heraklion, Crete (Emmanuel Ganotakis)
 - o Ahepa University Hospital of Thessaloniki (Konstantinos Tziomalo)
 - o Attikon University Hospital of Athens (Loukianos Rallidis)
 - o Tzaneio General Hospital of Piraeus (Dr. Eleni Bilianou)
- Criteria: Dutch Lipid Criteria
- LDL apheresis: Available (4 LDL apheresis centres)
- Planning to open more centres – now focusing on strong core of centres
- Pharma company – collecting the data and cooperate with ministry of health and scientific society – Hellenic Atherosclerosis Society (own the data but providing data to ministry)
- Mobile application, Informed consent – already prepared from company
- Workshop in Athens – 25 participants
- Prof. Tselepis is a candidate for the EAS board
- PCSK9 – available, limited quantity just for several patients – free from Sanofi
- Patients organization does exist

Slovakia

(Country Leader: Assoc. Prof. K. Raslova)

- The population of Slovakia is around 5,4 million
- National centre: Coordination Centre for Familial HLP – Slovak Medical University, Bratislava
- 19 other centres across the country
- 2000 patients in database (more than 20 years existing database)
- Long term cooperation between Assoc. Prof. Raslova and Dr. Vohnout
- Important cooperation between paediatrics and physicians
- FH programme - MedPed FH Slovakia (financed from different sources)
- MedPed FH SK structure (4 levels approach) – primary care, MedPed centres, Coordination Centre for familial HLP, Molecular diagnostics
- Criteria: Dutch Lipid Criteria, Simon Broome, MedPed US
- Genetic testing - around 500 patients (covered by grant)
- Sources - Health Insurance Companies, Slovak Medical University in Bratislava, Srdce rodiny n.o (non-profit foundation), research grants
- patient organization does exist
- PCSK9 is almost approved - available from November 2016, from January covered for limited number of patients



Ukraine

(Country Leader: Prof. Mitchenko)

- The population of Ukraine is more than 42 million
- Active FH center is located in Kiev at the State Institution “National Scientific Center” Acad. M.D. Strazhesko Institute of Cardiology» of National AMS of Ukraine
- Planned to open other 4 centres in future in cities: Dnipropetrovsk, Kharkiv, Lviv, Lutsk
- 81 patients with FH in database
- Criteria: MedPed, Dutch Lipid Criteria, Simon Broome
- FH program includes active detection of patients with suspected FH, with the further definition of the family history, lipid profile, the identification of markers of subclinical atherosclerosis, conducting stress tests, computer tomography coronary angiography (if the diagnosis is confirmed, patients' family is included)
- Genetic testing is not performed (very expensive)
- Health insurance is not provided from government

Uzbekistan

(Country Leader: Prof. A. Shek)

- The population of Uzbekistan is more than 31 million
- Republican Specialized Center of Cardiology (RSCC), Tashkent
- RSCC has got 12 branches in 13 regions of Uzbekistan
- FH centrum doesn't exist, but is planned to be open in future
- Criteria: Dutch Lipid Criteria
- FH program is at the very beginning
- 46 FH patients

Kyrgyzstan

(Country Leader: Prof. E. Mirrakhimov)

- The population of Kyrgyzstan is more than 6 million
- National centre: Kyrgyz Society of Cardiology + 3 other centres
- 7 patients in database
- FH program is at the very beginning
- Difficult to have patients with high cholesterol levels in lipid centres from physicians

Russia

(Country Leader: Prof. M. Ezhov)

- The population of Russia is more than 146 million
- 700 patients in database
- main centre is Cardiology Research Centre in Moscow
- Other 16 centres in 12 cities
- Criteria: Dutch Lipid Criteria
- LDL apheresis is available in some centres (very rare)
- Several patient organizations (the cooperation was great last year)

Next ScreenPro FH Project Meeting

- **The 2nd Prague European Days of Internal Medicine (PEDIM) – December 1 – 2, 2016 Prague**
 - ScreenPro FH Workshop (program is going to be send via email, active participation is greatly appreciated)
 - ScreenPro FH Project Leaders Meeting
 - ScreenPro FH Project is covering travel expenses and accommodation