



ScreenPro FH Project Meeting Minutes

June 3, 2016 St. Petersburg – the Symposium of the International Atherosclerosis Society

List of attendance

Chair: R. Ceska (Czech Republic)

Special Guest: G. Watts (Australia)

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

Country representatives:

Croatia: I. Pecin

Lebanon: E. M. Moubarak

Russia: A. V. Susekov

Czech Republic: T. Freiberger

Lithuania: S. Kutkiene

Slovakia: K. Raslova

Greece: A. Tselepis

Oman: K. Al-Rasadi

Slovenia: Z. Fras

Hungary: G. Paragh

Poland: A. Rynkiewicz

Welcome and introduction

The summary of activities

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

New ScreenPro FH Project members:

- Uzbekistan represented by Dr. Alexander Shek joined the ScreenPro FH Project in 2016
- New potential members: Lebanon – Prof. E. M. Moubarak, Oman – Dr. Khalid Al-Rasadi – both countries need help with building functional network of lipid clinics and would appreciate educational activities about screening and detecting patients

Web page

- The new web page www.screenprofh.com was launched at the beginning of the year 2016. We would like to ask all ScreenPro FH Project members to check out the website and share it among their colleagues. We would also like ScreenPro FH Project members to send us basic information about the situation in their countries as we've requested and send us their comments and suggestions concerning web page content.

FH book

- The English version of the book is ready to purchase and translation into local languages
- All ScreenPro FH Project members was informed about the **possibility to translate the book in their national language (National leaders could add description of the situation in their countries and become a co-author of the book)**
- The book is being published in a couple of months in Russia and also Kyrgyzstan is working on translation in Kyrgyz language
- ScreenPro FH Project is going to apply for financial support for FH book translation as well as for preparing and translation of educational booklet/brochure

The ScreenPro FH Project activities during the IAS Symposium in St. Petersburg

Familial hypercholesterolemia - G. Watts, R. Ceska - June 2, 2016 (meeting hall Azimut)

- Introduction (G. Watts, R. Ceska)
- The 10 Countries FH Study: opportunities for international networks (G. Watts)
- 50 years of FH in Czech Republic (R. Ceska)

ScreenPro FH Meeting – June 3, 2016 (meeting hall Murmansk)

ScreenPro FH Workshop - R. Ceska, G. Paragh - June 3, 2016 (meeting hall Munich)

- ScreenPro FH development (R. Ceska)
- FH in the Czech Republic: Data from a nationwide database (T. Freiberger)
- The development of FH screening in Hungary (G. Paragh)

- The prevalence of heterozygous familial hypercholesterolemia in the West Siberian region of the Russian Federation (A. Ershova)
- Familial hypercholesterolemia: Cascade screening diagnostic impact, a case report (A. Rocha)

The ScreenPro FH Project „Railway Model“

The “Railway Model” explains how to introduce ScreenPro FH Project to sponsors, partners, non-medical collaboratives, etc.

Railway	ScreenPro FH
Train driver	Country Leader
Train	Your (national) center
Stations	Lipid clinics
Track – railway system	National network
Schedule	Database
Transportation rules	Guidelines

The sponsoring model

ScreenPro FH Project is currently not able to find sponsoring for all member countries, we have to find a sponsors for general idea, for meetings and support the initiative. ScreenPro FH Project is going to organize an educational meetings, develop educational materials, provide know-how, offer the framework, etc.

Member countries should find local sponsors for their local activities.

Report form the ScreenPro FH countries

Greece (Prof. Tselepis)

- expecting 2000 patients by the end of the next year, 10 centres
- they have their own registry (E-CRF) that is connected to the Greece Ministry of Health,
- iphone application was developed and it's able to download
- financial sources are guaranteed for next year
- Prof. Tselepis is organizing EAS Advanced Course - October 13 - 15, 2016 in Athens, Greece

Russia (Prof. Susekov)

- want to include pediatricians and cardiologists in FH screening and education
- the main problem is that there are long distances in Russia, Prof. Susekov travels across Russia to connect centers with patients, problem lack of educated among pediatricians and cardiologists
- there isn't any FH register of heterozygotes in children
- Main achievement is education – create website – www.lipidology.ru - where you can find new topics connected with FH each month, international experts section at the web page – physicians could answer to questions about treatment
- Book – pocket lipid guidelines – distributed around Russia
- Going to extend main database – some other Russian cities are going to participate
- 2 programs in Russia – Prof. Susekov and Prof. Ezhov – both important and helpful

Lithuania (Dr. Kutkiene)

- Database is in paper version,
- 1 functional centre and other 4 centers are developing
- Try to contact with GP's to send patients to centres to do more analysis, Dutch criteria but some hospitals use another criteria
- Webinar across the country – Prof. Petrulioniene - all GP doctors should have more information about FH, they can also call the line for more information about the FH



Croatia (*Dr. Pecin*)

- Started online educational activity (public organisation) – www.cuvarisrca.hr - increase awareness about the CV diseases and they've also included FH as a topic
- You can read information about FH – included a lot of cardiologists and specialists – provided to public and doctors around country

Future events

ESC Congress – August 27 – 31, 2016, Rome

- **Next ScreenPro FH Project Meeting is being held August 28th or August 29th** during the ESC Congress in Rome (final date is going to be specified soon)

2nd Prague European Days of Internal Medicine (PEDIM) – December 1 – 2, 2016, Prague

- ScreenPro FH Meeting is being held during the PEDIM
- The 3 – 4 hours workshop on FH with international speakers is being organized
- **ScreenPro FH National Leaders' travel expenses are being covered by the ScreenPro FH Project** (flight ticket, 1 night accommodation, registration for the PEDIM congress)
- More information are coming soon

Future activities

Cooperation with other initiatives

- Prof. Gerald Watts presented his experiences from FH Australasia Network collaborative research project "10 Countries Study". ScreenPro FH Project is cooperating with this initiative and is going to use their recommendations and experiences.
- ScreenPro FH Project is ready to cooperate with FHSC, but nowadays the project priority is to develop a network of functional lipid centres/clinics. If the network is functional we are able to provide summary data from countries. However the national data are owned by the countries and this is a responsibility of the national leaders to decide in which form data will be provided.

Future development

- We are trying to find a way how to use the Czech MedPed database in all ScreenPro FH member countries. This possibility will be discussed and prepared in cooperation with Dr. Freiburger during the summer and will be presented at the ScreenPro FH Meeting in Rome

We would like to ask all ScreenPro FH Country Leaders to prepare a short information about the current situation in their countries as well as a short list of participating doctors (who is in charge in each country) and present it at the next ScreenPro FH Meeting in Rome.