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Press release

### **A dangerous heritage – to find and neutralize**

*Genetic heritage is responsible for every fifth case of the early myocardial infarction or stroke*

*The press-conference on “The family history against the ‘juvenile’ myocardial infarction” associated with the National Familial Hypercholesterolemia (FH) Day will take place in the State news network TASS on 14<sup>th</sup> of July. Medical experts (cardiologists, general practitioners, and prevention specialists), as well as representatives of the State Public Health and patients’ organizations, bloggers and journalists will discuss issues of early diagnosis and treatment of the familial hypercholesterolemia. They will touch sensitive topics of low motivation of Russian people to the regular preventive medical examination and instrumental check-up, in particular, the level of cholesterol and blood pressure measurement, the absence of patients and doctors outreach and awareness-raising work and as a consequence – the lack of knowledge about the familial hypercholesterolemia and its relationship with early myocardial infarctions and strokes. The experts will speak of what measures should be taken by the State to reverse the dramatic trend of increase of the incidence of ‘juvenile’ infarctions and strokes among Russians in the age of 20–40 years.*

Cardiovascular diseases (CVD) every year take the first place in the lethality among adults in RF. They take lives of 900 000 Russians every year. Despite the complex measures were taken by the State and the significant recent improvement of the sad statistics, today more than a half (53%) of deaths in Russia are caused by major cardiovascular events. Meanwhile, other countries demonstrate significantly lower figures of lethality from CVD: Germany – 35%, Great Britain – 29%, France – 22%. Particular attention is drawn by the fact that the CVD lethality rate of working age patients in RF is 4 times more than in the European Union. The major contributor to the preterm morbidity and lethality from coronary artery disease (CAD) and other cardiovascular diseases is the undiagnosed familial hypercholesterolemia (FH).

FH – one of the most widespread hereditary pathologies when the gene mutation is starting the uncontrollable increase of so-called ‘bad’ cholesterol (LDL cholesterol) and the development of atherosclerosis in young age and even in childhood. It is well known that FH increases the risk of early MI and stroke up to 20 times. These facts crash stereotypical view of high cholesterol and atherosclerosis issue as the problem of elderly.

Familial hypercholesterolemia – is not a new illness but doctors and patients, even more, do not know about it due to the lack of information on the disease, its causes, and risk factors. This implies the late diagnosis and low detection of the disease; less than 1% of patients know their diagnosis. From the experts’ estimate, the number of FH patients in Russia may reach 500 000 people (the official statistics is absent in the country).

The global experience demonstrates necessity of the implementation of the population-wide screening system for the prevention and the decrease of the rate of the early MI and strokes what will allow defining the risk group which includes people whose relatives died of or suffered from MI or stroke in the young age as well as diagnosing the disease in the early stage and beginning the effective treatment. The screening should be performed by specialists in lipid diagnostic and treatment centers that were already created in many European countries and recently began to be implemented in Russia.

The Russian familial hypercholesterolemia register is operating beginning from 2014. It includes 13 regions (Moscow, Sanct-Peterburg, Cheliabinsk, Samara, Novosibirsk, Ekaterinburg and others) with 28 medical institutions possessing the lipid center function. These institutions became the main bases for the diagnostics and treatment of patients suffering from severe disorders of the lipid metabolism. For the comparison: Great Britain has 164 lipid clinics, Germany has 210, USA and Canada – 52. Russian specialists are sure that the creation of the National network of lipid centers in our country will allow not only to diagnose the deadly disease but to save lives of the patients especially since the current development of the pharmacological industry, particularly the biotechnology, gives us the specific possibilities.

Up to the recent time, only two methods were effective in the decrease of cholesterol in FH patients namely statins and apheresis (blood cleaning). Doctors were not always successful in use of these methods, especially in serious patients. Patients' and doctors' hopes today are linked to the arrival of early biotechnological treatment what, in the experts' opinion, gives not only the real possibility to save patients with high and critical levels of cholesterol but allow decreasing the risk of cardiovascular accidents related to atherosclerosis. But, in the experts' opinion, neither availability of the innovation therapy nor even the shift of the FH patients' treatment paradigm will completely improve the early cardiovascular lethality rate if the FH awareness of doctors and patients will stay at the current low level, if the State institutions will not associate themselves with the solution of the problem and will not implement regulations for the timely medical care for the patients.

The country suffers enormous human and economic losses due to the excessive CVD mortality and high rate of 'juvenile' MI and strokes. For example, in 2009, the country had lost more than 2.8% of GDP due to the disability of patients suffering from cardiovascular accidents. Meanwhile, in the experts' opinion, only less than 1 US\$ is needed for the effective population prevention of early MI and strokes. Thus, the State National widespread familial hypercholesterolemia program is necessary in order to enlighten the medical community and the population, to implement the screening and early prevention, to create the National lipid centers system, and to approve the treatment standards. One of the major components of the population awareness program should become the annual National Russian Familial Hypercholesterolemia Day.

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***Note to the editor***

*National Russian Familial Hypercholesterolemia Day was introduced under the initiative of the Russian National Atherosclerosis Society. It is conducted to draw the attention of the power institutions, doctors and wider public to the issue, and to inform them on the novel methods of the prevention, diagnostics, and the treatment of the disease, as well as to bring up to date the hot questions risen in front of the National Public Health regarding the medical care for the patients suffering from FH. The first events were organized in 2016 in Sanct-Peterburg as the part of International Congress on Atherosclerosis dedicated to the memory of NN Anichkov.*

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