

A unique, global, research survey on women and FH launched on International Day of Action for Women's Health

May 28th has been commemorated by women's health advocates and their communities since 1987, when during the International Women's Health Meeting in Costa Rica, Latin American and Caribbean Women's Health Network (LACWHN) proposed to celebrate May 28 annually as the [International Day of Action for Women's Health](http://www.may28.org/about/) [link <http://www.may28.org/about/>].



Today, May 28th is a Day of Action recognized internationally wherein any organisation or individual can mobilise their communities around their own priority topic best suiting the local context. Any organisation working to advance women's health rights is welcome to launch May 28th activities, in the aim of ensuring women's health and well-being worldwide.

On this occasion, FH Europe partners with [Erasmus University Medical Center](#) and the Dutch expertise centre FH - [Stichting LEEFH](#) from the Netherlands, [University of Oslo, Department of Nutrition, National Advisory Unit on FH \(NKTforFH\)](#), Oslo University Hospital, from Norway, to launch officially an international survey on women and FH. The aim is to better understand how familial hypercholesterolemia (FH for short) affects women, their family planning decisions as well as health pre-, during and post pregnancy. The response goal is ambitious. "Together we hope to reach 1000 women globally. It is the first of its kind project initiated in collaboration between research centres in Norway, the Netherlands and our Network. To date no other research about women living with FH has been carried out at this scale. The collected data will help us improve lives of many women and their families living with inherited high cholesterol." says Magdalena Daccord, Chief Executive of FH Europe.

FH is the most common genetic condition causing dangerously high cholesterol. FH affects on average 1 person in 300, independently of their age, race, sex or lifestyle choices. Like many other genetic conditions, FH is inherited passed down through families. Each child of a person with FH has a 50% chance of inheriting the disorder. It is estimated that over 30 million people globally have FH, yet less than 10% are diagnosed. Undiagnosed FH leads to atherosclerosis, which causes cardiovascular disease, such as heart attacks and strokes, at a young age. Fortunately, FH can be treated by a healthy lifestyle in combination with cholesterol-lowering medication. The prevalence of FH is similar in men and women. However previous studies showed that FH poses an even larger risk of cardiovascular disease for women compared to men.

“In our pilot study, we found that young women with FH, lose several valuable years of treatment when discontinuing statins during planning of pregnancy, during the pregnancy and breastfeeding period. More than 20% of the women lost more than 4 years of treatment. We do not know if these periods of interrupted treatment increase the cardiovascular risk in FH women and we would like to find out more about this. Future guidelines on the management of FH women should consider taking into account the exposure of increased cholesterol during pregnancy-related off-statin periods” explains Prof Kirsten Bjørklund Holven from Norway.

The knowledge on cholesterol lowering medication in relation to pregnancy and breastfeeding periods in women with FH is scarce. Lipid-lowering drugs including statins are contraindicated during pregnancy and current ESC/EAS Guidelines recommend that lipid-lowering drugs are discontinued when pregnancy is planned, during pregnancy and during the breastfeeding period. When statins are discontinued, cholesterol levels increase to pre-treatment levels. “We want to investigate more about the causes and consequences of these periods on women’s health. We have developed anonymous online self-administered questionnaire. In this questionnaire, we are focusing on questions relating to pregnancy planning, breastfeeding, treatment in relation to these periods and information about health, worries and concern.” adds dr Jeanine Roeters Van Lennep from Holland.

Over the course of the next months the interdisciplinary team hopes to connect with women globally through the network of various patient groups, clinical centres and other relevant partners. A series of dedicated webinars and localised, translated surveys are planned to encourage female respondents to take part in this potentially ground-breaking and live saving research on women and FH. “Once we reach one thousand women, the next step will be to make the results available through an open-source publication to improve health literacy among women and the standard of care among clinicians. Depending on the findings, the intention is to develop specific medical and policy recommendations.” agree the three female project partners.