

Consent Form – Stored Sample

A study to assess how common Cholesteryl Ester Storage Disorder (CESD) is in patients with clinical features of Familial Hypercholesterolemia (FH).

Patient Name: **D.O.B.**

Please read each section and initial each box on the right before signing below

1. I confirm that I have read and understand the information sheet version 1.6 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I can withdraw from the study up until the time that my sample is analysed, without giving any reason and without my medical care or legal rights being affected. If I withdraw from the study after my sample has been analysed then I may choose not to receive the result of my test.	
3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from <i>Cardiff University</i> , the <i>relevant NHS organisations</i> and the <i>NHS All Wales FH Cascade Testing Service</i> , where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4. I agree that my GP will only be informed of my participation in this study if I request this by signing this box. My lipid consultant and BHF Nurse Specialist will be aware of my participation in this study.	
5. I consent for my stored DNA to be tested for genetic alterations that may cause my inherited high cholesterol including the genetic alteration which causes Cholesteryl Ester Storage Disorder.	
6. I agree to provide a fresh saliva or blood sample for DNA extraction if there is not enough of my stored DNA left for genetic testing.	
7. I consent for my information to be stored on the FH database. This is a secure NHS database which is only accessible to staff working within the All Wales FH Cascade Testing Service.	
8. I agree to take part in the study.	

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Name of study participant

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Date

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Signature

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Name of person taking consent

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Date

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Signature