



# UNIVERSITY OF CAMBRIDGE

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## **Age Related Macular Degeneration Information Sheet for Healthy Volunteers**

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Age Related Macular Degeneration (AMD) is a common eye condition usually occurring in people who are age 50 and older. It is a leading cause of vision loss in older adults. It gradually destroys the macula, the part of the eye that provides sharp, central vision needed for seeing objects clearly. In some people, AMD advances so slowly that vision loss does not occur for a long time. In others, the disorder progresses faster and may lead to a loss of vision in one or both eyes.

Living with such a condition can have a major impact on a person's quality of life and their family. We are working hard to gain a better understanding of the causes of AMD and are interested in finding out more about the genetic factors that determine an individual's risk. We would like to invite you to participate in a research study run by the University of Cambridge looking at the genetics of AMD. Please take the time to read the following information carefully and feel free to ask us if there is anything that is not clear or if you would simply like more information.

### **What is the purpose of the project?**

A number of risk factors for AMD have been identified, including several genetic variations within part of the immune system called the Complement System. The Complement System consists of a group of proteins circulating in the blood. When triggered, these proteins help the body fight off infection from bacteria and viruses. Increased activity within the Complement System can provide greater protection against bacterial infection but is also associated with an increased risk of developing AMD in old age. We would like to find out more about the genetic variations that determine an individual's risk of developing AMD and understand more about the Complement System to see how readily this increased activity can be reduced. We hope that information gained from this study will enable us, in the future, to be able to arrest or reverse the progress of AMD in at risk individuals.

### **Why have I been invited?**

You are being invited to take part in this study because you are a member of the Cambridge BioResource. We would like to test blood samples collected from people without AMD with different genetic make-up. We will measure complement activity levels in these blood samples to

try to work out how these activity levels can be reduced. Results will be compared with those obtained from patients diagnosed with AMD.

### **Do I have to take part?**

It is completely up to you to decide whether or not you wish to help with this study. If you do join, you will also be free to withdraw at any time and without having to give a reason.

### **What will happen if I agree to join the study?**

If you agree to participate the following things will happen:

- A member of the Cambridge BioResource team will contact you to arrange an appointment for you to provide a blood sample.
- You will be invited to attend the Cambridge BioResource research facility on the Addenbrooke's Hospital site to donate your sample. It may be possible for a member of the nursing team to visit you at your home / place of work if travel to Addenbrooke's is difficult.
- You will be given the opportunity to ask any questions and your questions will be answered in a way you understand.
- You will be asked to sign a consent form.
- A small blood sample (up to 50ml) will be collected from you by a qualified, experienced nurse.
- You will be asked to provide some information about certain lifestyle choices and behaviours e.g. smoking.

### **What are the risks and disadvantages of taking part in the AMD study?**

Participation in the project is unlikely to result in any harm. Individuals taking part in the study will be required to provide a small blood sample. Blood sampling can cause some discomfort when the needle is placed in the vein and the blood is drawn and there is also a possibility that a small bruise may develop. This project has been reviewed by a Research Ethics Committee to ensure that your rights and wellbeing are protected.

### **What are the benefits of participating in the AMD study?**

There will be no direct benefit to you by taking part but you will be making a contribution to science and future health. The information we will gain from this study will help lead to a better understanding of the links between genes, the complement system and an individual's risk of developing AMD. Your participation will contribute to improving healthcare provision and the long term treatment and prevention of this condition.

### **Can I know the results obtained from my study samples?**

It is not planned to routinely feedback any genetic or biochemical results obtained from your sample. In the unlikely event that a test result obtained from your sample indicates that you may benefit from a medical opinion, we would contact you and may invite you to provide a further sample that will be tested in an accredited laboratory.

**If I take part in the AMD study will my details be kept confidential?**

Yes. Best ethical and legal practice will be followed to ensure that all information collected about you will be handled in confidence. Any samples you provide will be labelled only with a unique sample study number before being transferred to the laboratory for testing. No personal identifiable information will be passed to the research team. Information from tests obtained on your samples will not be used or made available for any purpose other than for research. You will not be identified personally in any report or publication.

**Who is carrying out the research?**

This research project is being undertaken by the University of Cambridge in conjunction with the Institute of Ophthalmology, University College Hospital, London.

**Organisation and funding of the project**

This research project is being organised by the University of Cambridge in partnership with the Institute of Ophthalmology, University College Hospital, London. Funding for the study is being provided by GlaxoSmithKline and the Cambridge Enterprise. The study has received favourable opinion from the Human Biology Research Ethics Committee. Research Ethics Committees are independent bodies which review all research projects to ensure that your rights and wellbeing are upheld and risks are managed properly.

**What if I have any questions?**

If you would like to discuss any aspect of the information provided in this information sheet you can contact Professor Peter Lachmann:

Telephone number: 01223 766242 // email: [pjl1000@cam.ac.uk](mailto:pjl1000@cam.ac.uk)

Thank you for considering participating in the study.