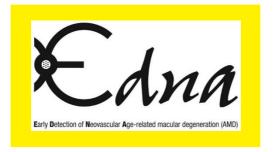
WINTER NEWSLETTER, 2017

E D N A Early **D**etection of **N**eovascular **A**ge-Related Macular Degeneration (AMD)

A research study co-ordinated by the Centre for Healthcare Randomised Controlled Trials at the University of Aberdeen and led by Professor Usha Chakravarthy from Queen's University Belfast.

The EDNA study is funded by the NIHR Health Technology Assessment programme

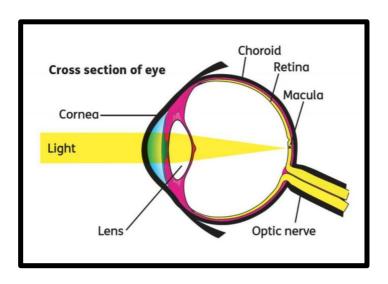


Thank you very much, on behalf of all the clinicians, nurses and researchers involved in the EDNA study, for being a participant in this important research on wet AMD.

You are one of over **500 people in 24 hospitals** across the UK taking part.

Everyone taking part in the EDNA study **has** neovascular **A**ge-Related **M**acular **D**egeneration (**AMD** or '**wet' AMD** for short) in one eye.

The other eye is being carefully monitored in EDNA, with the specific aim of detecting any signs in it indicating the onset of wet AMD. Early detection and treatment of wet AMD can prevent or reduce sight loss. Wet AMD affects the macula (part of the retina) at the back of the eye which is responsible for your central vision.



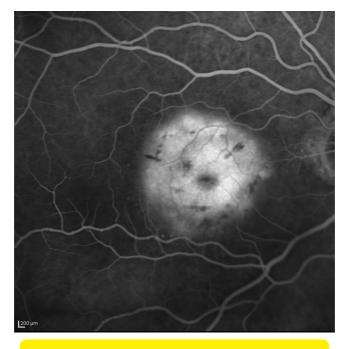
With your help, the EDNA study is trying to identify...

... the most reliable test that will show the earliest signs of wet AMD if and when it occurs in your 'good' eye.

How can we test for wet AMD?

You will already have had a **fluorescein scan** (**FFA**). This is presently the most reliable way of detecting wet AMD but it is a more invasive test involving the injection of a dye into a vein in your arm and taking photographs of the retina.

You will have had an identical test for your affected eye when your wet AMD was first diagnosed.



A fluorescein scan of the retina

In the EDNA study, each time you attend the eye clinic for ongoing treatment or monitoring of the eye with wet AMD, you will also have some tests on your other eye.

The EDNA study is collecting the information from these tests to see which may be most effective in early detection of wet AMD.

Don't forget - if you normally wear **glasses**, please make sure you **take them** to every eye clinic appointment

Checking for Wet AMD in your 'Good' Eye

There are **five tests** which are often used to check your eye health:

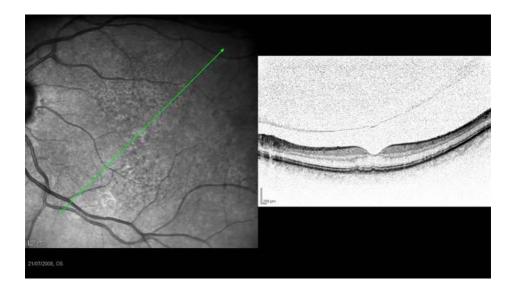
- Asking you if you have noticed any change in your good eye
- Using an Amsler chart a square grid. You can draw on it any distortion or blank regions
- Reading a chart this tests your sight to check if the number of letters you can see has changed

4. Eye examination – a special microscope to examine the retina and/or a photo of the inner part of your eye to look for signs of wet AMD.
Eye drops may be used to dilate your pupils and may make your vision blurred and sensitive to light for a while.



Photograph of the back of the eye (retina)

5. An OCT scan – OCT stands for Optical Coherence Tomography. This is a special type of scan of the retina which can reveal the signs of wet AMD. An example of a normal scan is shown below.



An OCT scan of the retina. The image on the right is a cross-section of the retina

If any of these five tests are abnormal, we will arrange a fluorescein scan (page 4) to check your good eye

We also ask you to have the fluorescein scan done after you have been in the EDNA study for eighteen months, even if there have been no obvious changes in your 'good' eye.

We do understand that some people find this scan unpleasant. However it is the most reliable, readily available test for wet AMD.

The fluorescein scan is important. It is used to tell us whether you **have** wet AMD or **don't have it**

What are the results from the EDNA study?

We are still collecting data for the study at the moment. We will follow all the EDNA patients for three years. The final results will be published in academic journals in early 2020. We will send a summary of this information to you.

Opportunity to take part in another research study

Your research nurse might have spoken to you about another research study – called FASBAT - linked with EDNA. This study is observing the effects of treatment for wet AMD.

If you would like to find out more information please contact your EDNA research nurse or the FASBAT study office **fasbat@york.nhs.uk.** You can also find out more online at **w3.abdn.ac.uk/hsru/FASBAT** **Do you want more information about wet AMD?** The Macular society has some great information about eye diseases

Their helpline number is 0300 3030 111

Visit www.macularsociety.org for more

Monitoring your eye health

Our patients, who help us manage our research, suggested you might like to take notes of which tests you have done at your visits. We have provided you with a template diary. You could also keep track of any results you want or you think are important.

It's up to you how you use this – it is not compulsory and it isn't part of the EDNA study. The EDNA study office is based in Aberdeen in Scotland. We have a website where you can find out more: **w3.abdn.ac.uk/hsru/EDNA**

You can also contact us on **edna@abdn.ac.uk** if you have any questions about EDNA.

However, if you have questions about your eye health you should contact your eye doctor or optician.

Let us know what you think about the diary. Please get in touch if you would like more copies or want to suggest changes that will help you.