

FECD Family History Information Flyer

What Family History Means:

As part of the **Fuchs' Endothelial Corneal Dystrophy (FECD) Genetics Multi-center study**, we wish to inform you of how important family history is in helping health research uncover the basis for many health problems. Family history refers to health information about you and your close relatives and is one of the most important risk factors for health problems such as heart disease, stroke, diabetes and cancer. (A risk factor is anything that increases your chance of getting a disease.) Our study is focusing on the risk factors and genes associated with developing FECD. Family members share their genes, as well as their environment, lifestyles and habits. A family history helps identify people at increased risk for disease because it reflects both a person's genes and these other shared risk factors. Having a family member with a disease suggests that you may have a higher chance of developing that disease than someone without a similar family history. It does not mean that you will definitely develop the disease. Genes are only one of many factors that contribute to disease.



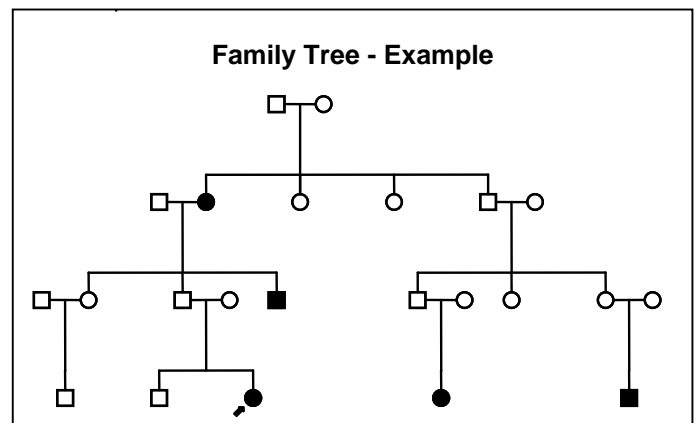
What Family History is needed for the FECD Genetics Multi-Center Study?

For the FECD Genetics Multi-Center Study, we will ask participants to fill out a Family History Form. In this form we will ask about the participant's birth parents; their names (first name and last initial), whether they are deceased or living, what city they live in (to see if they are near a study center), and whether they have (or had) a history of FECD. We will also ask the same questions about the participant's brothers and sisters. Finally, we will ask participants if they have any other relatives such as children, aunts, uncles, nieces, nephews, cousins, grandparents, etc. who they suspect or know have FECD. For any relative who the participant suspects or knows has FECD, we will ask for the following information: relative's name, relative's parents' names, and the city in

which the relative lives (again to see if they live near a study center). To maintain confidentiality, we will only ask for the first name and last initial of all relatives, not the full name. Also, the participant's name will NOT be shown on the Family History Form, but instead a number. We will NOT contact any of your relatives about joining the study without first receiving contact (such as a phone call or a returned reply card) from the interested relative.

How you can draw your Family Tree:

The CDC (Center for Disease Control) has a website which you can use to construct your family tree: <https://familyhistory.hhs.gov>. This website is called "My Family Health Portrait". On the back of this flyer we are including instructions on how to draw your family tree specific to **FECD** using this website. This is completely voluntary. Also, the US government does NOT have access to the information entered on the "My Family Health Portrait" website. This information is stored on your computer. (See the privacy and security policy link at the bottom of the webpage.) If you are participating in this study, it is helpful if you are able to provide a picture of your family tree (including those who have FECD); however, this is NOT required to become a participant. Should you become a participant to the study, the coordinator at your local site will review your family history during your office visit.



FECD Family History Information Flyer

How you can draw your Family Tree (specific to Fuchs' Endothelial Corneal Dystrophy (FECD):

1. Go to the website: <https://familyhistory.hhs.gov>
2. Click on "Create a Family History" and then fill in your name, age, etc. under 'My Profile – Personal Information'. When finished click 'Next'.
3. Now fill in your gender (Male/Female) and indicate if you are an identical twin. Fill in whether or not you have the diseases listed (optional). If you do indicate you had a disease, select the age (or approximate age) when you were first diagnosed.
4. For this study we are particularly interested in **FECD**. To add this disease to the list, scroll down, and under 'Additional Diseases (Optional)' type in "FECD". Select the approximate age in which you were first diagnosed. Click 'Next' when you are finished filling out the information about yourself.
5. Next, follow the instructions on the website and provide information about your sisters, brothers, daughters, sons, half sisters, and half brothers. Only add those who are blood relatives and not adopted or step relatives. If you don't know the information just leave it blank. Again, since we are particularly interested in FECD, be sure to add this disease to the list (under 'Additional Diseases') for any relative who you think or know has FECD.
6. When you have finished entering information about your relatives, the screen will show "Congratulations!". Now click on the "Go to My Family" button. You and your family will be listed on the right. You may edit any of the information you entered by clicking on the edit button. You don't have to have the information complete for everyone, but we do hope you can draw a family tree indicating ALL relatives who have (or you suspect have) FECD. To add additional relatives with FECD, click on 'Add Family (aunts, uncles, etc.)' link which is under 'Actions' on the right side of the screen. Follow the instructions on the website to add relatives to your family tree. A form will be displayed for each person as before. Fill out the information in the form and be sure to write 'FECD' under 'Additional Diseases' if the relative has FECD.
7. To Save click 'Save My Health Information to My Computer'. Follow the instructions on the website.
8. After saving, you can print out your family tree. Here we are providing instructions on how to print your family tree in a way that will be useful to the FECD Genetics Study. Go back to the 'My Family' screen and click the 'View Reports' link which is under 'Actions' on the right side of the screen. For 'Report Type' select 'Drawing', for 'Display Names' select "Yes", for "Display My Personal Information" select "No", **for "Highlight Options" select "FECD"**. Next click on View Report.
9. Your family tree should appear on the screen. To print, click on "Print this report". A pdf file of the family tree should appear (this may take some time depending on the size of the family tree). In the pdf file, go to the "File" menu and then 'Print'. Click 'Ok' to print your family tree.

Now you should have a printout of your family tree. If you will be participating in the FECD Genetics study, be sure to bring the printout with you. If you wish to work further with your family tree (add more relatives, other diseases) feel free to return to the website above and load your saved family tree.

If you have any questions while constructing your family tree you may click on the "Help with this page" button, available throughout the CDC "My Family Health Portrait" website. This website is operated by the CDC and is completely separate from the FECD Genetics Multi-Center Study, however we may be able to assist you as you use this website: FECD Genetics Study hotline: 1-877-844-1114.