

# Vitiligo Genes?

**Do you have vitiligo, or have you had it in the past? Or does someone in your family have vitiligo? If so, would you or they be willing to take part in a major research project on vitiligo?**

We and an international team of scientists are looking for genes for vitiligo. Our goal is eventually to be able to discover the causes of vitiligo, to identify people at risk for developing vitiligo, and ultimately to find a better treatment, a cure, or even a way to prevent vitiligo.

**Progress:** We have found out quite a lot about vitiligo itself, for example how often it runs in families, and which other disorders like thyroid disease can run in the same families. "Inheriting" vitiligo seems to depend on several genes rather than one, and genes may play a part in vitiligo even in people who have no relatives with vitiligo. So far we have identified four definite loci (the broad locations of key genes, on one of the chromosomes,) for increased risk of vitiligo, and four other possible loci. Most of these are being studied further. One of them involved a gene connected to pigment-cell development, but was quite rare. Another has now proved to be a common gene alteration on chromosome 17, which affects a regulator in the immune system and is associated with other immune disorders, like autoimmune diabetes, as well as vitiligo. This finding was published in March 2007, in the New England Journal of Medicine.

Anyone with vitiligo will be valuable for us to study in the next part of the program, not just those who also have relatives with vitiligo. So if you or your relative with vitiligo are prepared to help us and vitiligo sufferers by providing a saliva sample (for a few participants we may request a small blood sample), and some health and family information, please take a moment to fill in and return this questionnaire. Your help will be greatly appreciated.

Note: it may be some time before we contact you for your sample, because this is a large study and may take a long time to complete.

**Please fill in the form as soon as possible, and return it either by e-mail to:**

**aamadi@sgul.ac.uk**

**or by mail to:**

**Anita Amadi-Myers, Vitiligo Genes Project  
Centre for Molecular and Metabolic Signalling  
Division of Basic Medical Sciences (Anatomy)  
St George's, University of London  
Cranmer Terrace,  
London  
SW17 0RE**

**We thank you very much for your help, and look forward to hearing from you.**

*Prof. Richard Spritz, University of Colorado, USA*

*Prof. Dorothy Bennett, St George's, University of London, UK*

*Dr. Pamela Fain, University of Colorado, USA*

## UK VITILIGO FAMILY QUESTIONNAIRE

This should be filled in by (or for) one person in your family who has vitiligo. Please write clearly. If there is not enough room for your answers, please continue on a sheet of paper and attach it to this form. Note: all personal information will be kept in confidence and not used for anything other than this study.

Important: When we ask about brothers, sisters, parents etc, we mean "blood"-relatives (not relatives by marriage or adoption). Similarly, "brothers / sisters" means people with the same mother and father, not half-brothers etc.

1. If you are the person with vitiligo, please go to question 2. If you are filling in this form for a child or for someone else, please enter their name here:

\_\_\_\_\_

(in which case, from question 3 onwards, "you" means the person with vitiligo).

2. Please enter your name and address. \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

3. What is your age? \_\_\_\_\_, sex? \_\_\_\_\_, and age when vitiligo first appeared? \_\_\_\_\_

4. How much of your skin would you say is affected by vitiligo at present? Tick one box.

Up to 25%       26-50%       51-75%       76-100%

5. Would you be willing to take part in this project by giving a saliva or blood sample?

\_\_\_\_\_

Of course you are free to change your mind later about this.

6. Please may we have some contact details (strictly for this study; they will not be given to anyone else)? Tel: Daytime \_\_\_\_\_ Evening \_\_\_\_\_

E-mail address \_\_\_\_\_

7. Do you have a brother(s) or sister(s) willing to give a saliva or blood sample? If so, please provide the following for each one:

Name	Age	Sex	Age when vitiligo first appeared (write N if they never had vitiligo)
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\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

8. Is your mother alive? \_\_\_\_\_ If so, would she be willing to give a saliva or blood sample? \_\_\_\_\_

9. Is your father alive? \_\_\_\_\_ If so, would he be willing to give a saliva or blood sample? \_\_\_\_\_

10. Who else in your family has vitiligo? Please give their age when it first appeared, if known. For example, mother (10), son (5). \_\_\_\_\_

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11. Please briefly describe any special medical conditions that you or any of your relatives have, such as diabetes, pernicious anaemia or thyroid problems (not infections or injuries). For diabetes, please say whether it began in childhood or as an adult, and whether insulin was needed, if known.

Condition Who has condition (for example, aunt, me)

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12. How many brothers do you have? \_\_\_\_\_ How many sisters? \_\_\_\_\_

13. How many brothers does your mother have? \_\_\_\_\_ How many sisters? \_\_\_\_\_

14. How many brothers does your father have? \_\_\_\_\_ How many sisters? \_\_\_\_\_

15. How many children do you have? \_\_\_\_\_

16. If you have a child with vitiligo, is their other parent willing to give saliva or blood?

\_\_\_\_\_

And are you and your child willing for the child to give saliva or blood? \_\_\_\_\_

17. Has your spouse/partner ever had vitiligo? \_\_\_\_\_ Has anyone else in their family ever had vitiligo? \_\_\_\_\_

18. Please tick whichever of the following ethnic groups fits you best

- |   |                                      |   |
|---|--------------------------------------|---|
| <input type="checkbox"/> Afro-Caribbean | <input type="checkbox"/> Pakistani   | <input type="checkbox"/> White/ Caucasian       |
| <input type="checkbox"/> Bangladeshi    | <input type="checkbox"/> Vietnamese  | <input type="checkbox"/> Mixed race             |
| <input type="checkbox"/> Chinese        | <input type="checkbox"/> Other Asian | <input type="checkbox"/> Other (please specify) |
| <input type="checkbox"/> Indian         | <input type="checkbox"/> Turkish     | _____   |

19. If you answered Mixed race, please explain

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20. What are your eye colour and natural hair colour (if hair grey, give colour before greying)?

Eye Colour: \_\_\_\_\_ Hair Colour: \_\_\_\_\_.

If there is any other information you think may be useful to us, please add it below or on another sheet. *Thank you very much for your help.*