



Friend,

### Can You Spare A Few Minutes To Help Us Fight Vitiligo?

By taking a little time to fill in this questionnaire, you can help us find a cure for vitiligo.

Your responses will be part of the clinical data we are gathering for future research projects. They will also help us facilitate collaboration between scientists and ultimately to develop new therapies.

We are a registered 501(c)3 non-profit organization, dedicated to funding and fast-tracking vitiligo research worldwide. We are the *only* non-profit organization that addresses every phase of vitiligo drug development, from research lab all the way to clinic.

The data you provide will be shared, but we respect your privacy and don't ask for any personal information – this questionnaire is completely anonymous. Please refer to VRF's privacy policy, which explains your rights and responsibilities with respect to the information being collected (<http://vrfoundation.org/privacy-statement>)

Please try to answer all the questions to the best of your knowledge and make sure your handwriting is readable. Then, simply mail back in the pre-paid envelope provided.

If you have received this via email or downloaded from the website, the PDF is interactive, so you can answer questions on the computer, save the file and send it to [info@vrfoundation.org](mailto:info@vrfoundation.org)

Thank you,

Yan Valle

CEO Vitiligo Research Foundation

Today's date: (day/month/year)

## ORIGINS

### 1. Date of birth:

Day                      Month                      Year

### 2. Which City and Country were you BORN in?

3. SEX (select one)                      Male                      Female

### 4. What best describes your ETHNICITY? (select one)

- African American / African
- Chinese / Korean / Japanese
- Hispanic
- Indian / Pakistani
- Middle Eastern
- White / Caucasian
- Mixed Race
- Other Ethnic Group (please specify)

### 5. What is your EYE COLOR? (select one)

- Blue/Grey
- Green/Hazel
- Tan/Brown

## HISTORY OF VITILIGO

### 6. At what AGE did you first notice signs of vitiligo? (select one)

- |             |             |
|-------------|-------------|
| 0-5 Years   | 41-50 Years |
| 6-12 Years  | 51-60 Years |
| 13-20 Years | 61-70 Years |
| 21-30 Years | 71-80 Years |
| 31-40 Years | 80+ Years   |

### 7. Vitiligo signs FIRST appeared on (select all applicable)

- |  |            |
|--|------------|
| Head/Neck/Face                                 | Lips       |
| Hand/Foot                                      | Elbow/Knee |
| Groin  | Genitals   |
| Trunk  | Armpit     |
| Arm/Leg (excluding hands, elbows, feet, knees) |            |
| Mucous membrane (inside mouth, nose etc.)      |            |
| Other (please specify)                         |            |

**8. In your opinion, what CAUSED your vitiligo?**

*(select all applicable):*

- Emotional distress
- Physical skin damage
- Pregnancy or Childbirth
- Medication side-effect *(name of the drug)*

Cosmetic or Hair product *(what was it?)*

- Deodorant or perfume
- Sunburn or prolonged sun exposure
- Rubber product *(i.e. gloves):*

Exposure to hazardous materials *(what was it?)*

Vaccination *(name of vaccine)*

Other *(please explain)*

Not sure

**9. Was your vitiligo active LATELY? (select one)**

- Actively spreading in the last month or two
- Stable for more than 3 months

**10. How did your vitiligo progress EARLIER? It was: (select one)**

- Quick, short burst, then limited spreading
- Slow, progressive spreading over several years

**11. Did you notice skin itching or redness BEFORE the white patch appeared? (select one)**

- No
- Yes

**VITILIGO DESCRIPTION**

**12. What best describes your normal skin COLOR? (select one)**

- |              |                  |
|--------------|------------------|
| Pale white   | Light brown      |
| Fair         | Brown            |
| Darker white | Dark brown/black |

**13. What does your vitiligo LOOK like? (select one)**

**Generalized form:**

- Scattered patches all over *(Vitiligo vulgaris)*
- Face, head, hands and feet *(Acrofacial)*
- Nearly complete loss of color *(Universal)*

**Localized form:**

- Mucous membranes alone *(Mucosal)*
- A confined, stable area of color loss *(Focal)*
- Patches only on one side of the body *(Segmental)*

**Mixed form** *(combines Segmental, Acrofacial and/or Generalized distribution)*

**14. To what DEGREE is your skin affected now? (select one)**

- |               |         |
|---------------|---------|
| Less than 10% | 50-75%  |
| 10-25%        | 75-100% |
| 25-50%        |         |

*(As a reference, your palm area is equivalent to approximately 1% of your total body surface)*

**VITILIGO TREATMENTS**

Please provide details of all your vitiligo treatments to date.

**15. Type of TREATMENTS received to date (select all applicable, name it later)**

**Before Latest**

- Light therapy, laser- or phototherapy
- Systemic (pills, injections)
- Topical (creams)
- Surgical
- Psychological counseling
- Traditional *(indigenous or folk)* medicine
- Complementary *(i.e. vitamins, food supplements)*

**Name of medicine(s) used (if any selected above)**

Before:

Latest:

**16. At the time of the latest treatment, your vitiligo was** *(select one)*

- Active *(spreading in the last month or two)*
- Stable *(no progression over last 3 months before treatment)*

**17. As a RESULT of the latest treatment, your vitiligo** *(select one)*

- Continued, or new white patches appeared
- Continued, but slowed significantly
- Completely stopped, but patches still remain
- Almost or completely disappeared

**18. The latest treatment DURATION was:**

\_\_\_\_\_ months.

**19. How did you FOLLOW the treatment protocol?** *(select one)*

- Rigorously: maybe skipped one or two only
- Somewhat closely: maybe skipped a few or more
- Loosely, or had to stop early

**20. After treatment, did vitiligo RE-APPEAR or start spreading again?**

- No
- Yes, it begun after \_\_\_\_\_ months.

**21. Have you noticed that medications taken for OTHER health conditions had an effect on your vitiligo?**

- No
- Yes, it was *(medication name)*

and it *(select one)*

- Improved or Worsened your vitiligo,
- Temporarily or Permanently.

## SKIN CONDITION

**22. Do you have any GREY HAIR?** *(select one)*

- No, or maybe just a few Quite a lot
- A reasonable amount I'm nearly all grey

**23. Do you have a family history of early hair greying?**

- No Yes *(select one)*

**24. Do you SUNBURN easily?** *(select one)*

- No Yes

**25. Have you noticed a HALO NEVUS anywhere on your skin?** *(A 'halo nevus' is a benign mole on the skin with a white ring or "halo" around it.)*

- No Yes *(select one)*

## OTHER CONDITIONS

**26. What ALLERGIES do you have, if any?** *(select all applicable and provide details below)*

- |               |                               |
|---------------|-------------------------------|
| None          | Food allergens or intolerance |
| Medications   | Substances you touch          |
| Insect stings | Airborne allergens            |
| Sun reactions | Other <i>(please specify)</i> |

**27. Do you have any CHRONIC diseases other than vitiligo?** *(select all applicable)*

- |          |           |                             |
|----------|-----------|-----------------------------|
| None     | Psoriasis | Rheumatoid arthritis        |
| Diabetes | Thyroid   | Other <i>(what is it?):</i> |

**28. Have you ever been diagnosed with melanoma or other SKIN CANCER?** *(select one)*

- No
- Yes, it was *(skin cancer name):*

**29. Do you have close blood RELATIVES who suffer from vitiligo?** *(select all applicable)*

- |                  |                  |
|------------------|------------------|
| Brother          | Sister           |
| Father           | Mother           |
| Father's brother | Mother's brother |
| Father's sister  | Mother's sister  |

## IMPACT

### 30. What is the approximate COST of your vitiligo treatment and/or camouflage to date?

*(US\$ or equivalent)*

Nothing	\$1,001-\$10,000
Under \$50	\$10,001-\$20,000
\$51-500	More than \$20,000
\$501-\$1,000	Not sure

## PHOTOS

If you're uncertain about your skin condition, feel free to attach a photo of the affected area.

## THANKS!

Thank you for taking the time to complete this questionnaire, you are making a big contribution to the fight against vitiligo.

Please send it to us now, by email or post using our pre-paid envelope.

The contents of this Vitiligo Questionnaire are based on the Vitiligo Health Record for clinicians and can be downloaded from <http://vrfoundation.org/foundation/download-center>

## QUESTIONS & ANSWERS

We have put together a packet of information on vitiligo for you. It is now available for download in Chinese, Croatian, English, German, Italian, Macedonian and Russian at <http://vrfoundation.org/foundation/publications>

If you have questions regarding this questionnaire, future research projects or our organization in general, please visit our website or send us an email.

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