

QUESTIONNAIRE FOR PERSONS WITH WEGENER'S GRANULOMATOSIS

(To be filled out by patient.)

Name: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_  
(optional) First Middle Last mm dd yr

First, we would like to know some general information about you. (Please circle the **number** which corresponds to your response or fill in appropriate blanks.)

- |   |   |
|---|---|
| 1. What is your gender? Male 1<br>Female 2  | 2. In what year were you born? 19 __ __   |
| 3. How would you classify your race?<br>White 1<br>African-American 2<br>Hispanic 3<br>Pacific Islander 4<br>Asian 5<br>Native American 6<br>Other 7<br>please specify: _____ | 4. a) What is the highest level of school you every achieved?<br>(even if you did not graduate)<br>Elementary 1<br>High School 2<br>College 3<br>Graduate School 4<br>Trade or technical school 5<br>4. b) Did you graduate from school?<br>Yes 1<br>No 2 |

The next few questions will ask about the doctors who care for your Wegener's granulomatosis (WG). (Please circle the **number** which corresponds to your response, or fill in the blanks.)

- |  |  |
|--|--|
| 5. Do you have one main doctor who provides and coordinates all of your care for WG?<br>Yes 1 If yes, what is the name of your doctor? _____<br>No 2 First Last  | 7. What other kinds of doctors care for your WG?<br>(circle <b>all</b> that apply)<br>Rheumatologist 1<br>Nephrologist (kidney specialist) 2<br>Ear, Nose & Throat specialist 3<br>Pulmonary (lungs) specialist 4<br>Family practitioner 5<br>General internist 6<br>Other 7<br>please specify: _____<br>Do not know ..... 8 |
| 6. Is this doctor a:<br>Rheumatologist 1<br>Nephrologist (kidney specialist) 2<br>Ear, Nose & Throat specialist 3<br>Pulmonary (lungs) specialist 4<br>Family practitioner 5<br>General internist 6<br>Other 7<br>please specify: _____<br>Do not know ..... 8 | 7. What other kinds of doctors care for your WG?<br>(circle <b>all</b> that apply)<br>Rheumatologist 1<br>Nephrologist (kidney specialist) 2<br>Ear, Nose & Throat specialist 3<br>Pulmonary (lungs) specialist 4<br>Family practitioner 5<br>General internist 6<br>Other 7<br>please specify: _____<br>Do not know 8       |

Now, we will ask you a few questions about how WG has affected you.

- |  |                                    |
|--|------------------------------------|
| 8. When did you first begin to have symptoms of WG?  | 19 __ __                           |
| 9. When did a doctor first tell you that you have WG?  | 19 __ __                           |
| 10. a) Did you see more than one doctor before you were diagnosed?   | Yes 1<br>No 2<br>Cannot remember 3 |
| b) If yes, how many physicians did you see before the diagnosis was made?  | __ __                              |
| 11. During the period of time before your diagnosis, was it suggested that the problem was "psychosomatic"?<br>(That it was "all in your head".) | Yes 1<br>No 2                      |

12. As best you can recall, when you were **first** diagnosed with WG, which parts of your body were originally involved?

- (Circle all that apply.)
- |                          |    |
|--------------------------|----|
| Mouth                    | 1  |
| Nose                     | 2  |
| Sinuses                  | 3  |
| Ears                     | 4  |
| Breathing tube (trachea) | 5  |
| Eyes                     | 6  |
| Skin                     | 7  |
| Joints                   | 8  |
| Muscles                  | 9  |
| Lungs                    | 10 |
| Kidneys                  | 11 |
| Intestines               | 12 |
| Others                   | 13 |

please specify: \_\_\_\_\_  
\_\_\_\_\_

13. a) Since you were first diagnosed with WG, have you had **additional** parts of your body affected by WG?

Yes ..... 1

No ..... 2

b) If yes, which parts of your body? (Circle all that apply.)

- |                          |    |
|--------------------------|----|
| Mouth                    | 1  |
| Nose                     | 2  |
| Sinuses                  | 3  |
| Ears                     | 4  |
| Breathing tube (trachea) | 5  |
| Eyes                     | 6  |
| Skin                     | 7  |
| Joints                   | 8  |
| Muscles                  | 9  |
| Lungs                    | 10 |
| Kidneys                  | 11 |
| Intestines               | 12 |
| Others                   | 13 |

please specify: \_\_\_\_\_  
\_\_\_\_\_

14. Has your illness required surgical procedure(s) since it started? If you, please circle all that apply (including procedures done for establishing the diagnosis).

- |  |    |
|--|----|
| None   | 1  |
| Ear tubes  | 2  |
| Tear ducts   | 3  |
| Sinus surgery  | 4  |
| Sinus surgery more than one time   | 5  |
| Tracheal (breathing tube) stretching                                       | 6  |
| Tracheotomy (hole in your breathing tube)                                  | 7  |
| Nasal biopsy   | 8  |
| Needle lung biopsy (through the skin or at bronchoscopy-tube to the lungs) | 9  |
| Open lung biopsy (surgery to remove part of the lung)                      | 10 |
| Kidney biopsy .  | 11 |
| Kidney transplantation   | 12 |
| Skin biopsy  | 13 |
| Nerve biopsy   | 14 |
| Eye surgery  | 15 |
| Other surgery  | 16 |

please list: \_\_\_\_\_  
\_\_\_\_\_

15. How would you estimate the **current** activity of your WG?
- |               |   |
|---------------|---|
| In remission  | 1 |
| Mildly active | 2 |
| Very active   | 3 |
16. a) Are you currently being treated with medications for WG?
- |     |   |
|-----|---|
| Yes | 1 |
| No  | 2 |
- b) If yes, are you taking?
- |                              |    |             |   |
|------------------------------|----|-------------|---|
| Yes                          | No | Do not know |   |
| Steroids (prednisone)        | 1  | 2           | 3 |
| Methotrexate                 | 1  | 2           | 3 |
| Imuran (azathioprine)        | 1  | 2           | 3 |
| Cytosan (cyclophosphamide)   | 1  | 2           | 3 |
| Bactrim (trimethoprim/sulfa) | 1  | 2           | 3 |
| Other medications            | 1  | 2           | 3 |
17. a) Compare your health today with your health when you were first diagnosed with WG, would you say your health now is:
- |                          |   |
|--------------------------|---|
| Much better              | 1 |
| Better                   | 2 |
| Same                     | 3 |
| Worse                    | 4 |
| Much worse               | 5 |
| Changing too much to say | 6 |
- b) How do you think your health will be in the future compared to how it is today?
- |                          |   |
|--------------------------|---|
| Much better              | 1 |
| Better                   | 2 |
| Same                     | 3 |
| Worse                    | 4 |
| Much worse               | 5 |
| Changing too much to say | 6 |
18. How would you rate the **present** impact of the disease (including side effects of therapy) on your ability to perform your daily activities at home and/or at work?
- |   |   |
|---|---|
| No effect (no loss of ability to do all things you want to do)  | 1 |
| Periodic effect (periods of worsening that improved to normal or near normal following therapy)   | 2 |
| Permanent inability to do at least some usual activities at home or work<br>(for example, inability to drive or inability to participate in a favorite sport) | 3 |
19. If you were asked to rate how much the Wegener's granulomatosis has affected your daily life on a scale of 1 to 10, what number would you choose?
- |   |   |
|---|---|
| _____   _____   _____   _____   _____   _____   _____   _____   _____   _____ |   |
| 1      2      3      4      5      6      7      8      9      10             |   |
| Not at all: I can do anything I want to do.                                   | Has changed everything: I can not provide for my basic needs at home (like washing, dressing, or eating). |
20. If you were asked to rate how much the Wegener's granulomatosis has affected your daily life when you were **first** diagnosed with the disease, on a scale of 1 to 10, what number would you choose?
- |   |   |
|---|---|
| _____   _____   _____   _____   _____   _____   _____   _____   _____   _____ |   |
| 1      2      3      4      5      6      7      8      9      10             |   |
| Not at all: I could do anything I wanted to do.                               | Has changed everything: I could not provide for my basic needs at home (like washing, dressing, or eating). |
- The next section asks about chronic medical problems that you may have in addition to WG, or as a complication of its treatment.
21. a) Do you have diabetes (high blood sugar)?
- |     |   |
|-----|---|
| No  | 1 |
| Yes | 2 |
- b) If yes, when were you diagnosed with diabetes?
- |                           |   |
|---------------------------|---|
| BEFORE diagnosis of WG    | 1 |
| AT THE SAME TIME as WG    | 2 |
| AFTER the diagnosis of WG | 3 |

22. a) Do you have hypertension (high blood pressure)?  
 No 1  
 Yes 2
- b) If yes, when were you diagnosed with hypertension?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3
23. a) Do you have heart disease (angina or heart attack and/or heart failure)?  
 No 1  
 Yes 2
- b) If yes, when were you diagnosed with heart disease?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3
24. a) Do you have liver disease?  
 No 1  
 Yes 2
- b) If yes, when were you diagnosed with liver disease?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3
25. a) Do you have asthma or emphysema?  
 No 1  
 Yes 2
- b) If yes, when were you diagnosed with asthma or emphysema?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3
26. a) Do you have arthritis:  
 No 1  
 Yes 2
- b) If yes, when were you diagnosed with arthritis?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3
27. a) Do you have cataracts?  
 No 1  
 Yes 2
- b) If yes, when were you diagnosed with cataracts?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3
28. a) Are you legally blind?  
 No 1  
 Yes 2
- b) If yes, when were you declared legally blind?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3
29. a) Did you have a stroke?  
 No 1  
 Yes 2
- b) If yes, when were you diagnosed with a stroke?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3
30. a) Did you have cancer?  
 No 1  
 Yes 2
- b) If yes, when were you diagnosed with cancer?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3
- c) Name the type of cancer(s) you were found to have: \_\_\_\_\_
31. a) Do you have a peptic ulcer (an ulcer in your stomach or first part of the intestine)?  
 No 1  
 Yes 2
- b) If yes, when were you diagnosed with an ulcer?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3
32. a) Did you suffer from avascular necrosis of the hip [AVN] (collapse and fracture of the top or round part of the hip bone)?  
 No 1  
 Yes 2
- b) If yes, when were you diagnosed with AVN?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3  
 BEFORE and AFTER the diagnosis of WG 4

33. a) Were you diagnosed with osteoporosis (“brittle bones”)?  
 No 1  
 Yes 2
- b) If yes, when were you diagnosed with osteoporosis?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3  
 BEFORE and AFTER the diagnosis of WG 4
34. a) Have you been diagnosed with osteoporotic fractures (“brittle bones”) of the spine?  
 No 1  
 Yes 2
- b) If yes, when were you diagnosed with osteoporotic fractures of the spine?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3  
 BEFORE and AFTER the diagnosis of WG 4
35. a) Have you been diagnosed with other broken bones?  
 No 1  
 Yes 2
- b) If yes, when were you diagnosed with other fractures?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3  
 BEFORE and AFTER the diagnosis of WG 4
36. a) Have you had to undergo dialysis for kidney failure?  
 No 1  
 Yes 2
- b) If yes, when were you on dialysis?  
 BEFORE diagnosis of WG 1  
 AT THE SAME TIME as WG 2  
 AFTER the diagnosis of WG 3
37. Did you have a kidney transplant? No 1  
 Yes 2

The next section will concentrate on issues regarding employment.

38. Have you ever been employed full time, for more than a year before your diagnosis? Yes 1  
 No 2

**IF NO, GO TO QUESTION 55**

39. a) Were you employed at the time of your diagnosis?  
 Yes 1  
 No 2
- b) If yes, were you working:  
 Full time (at least 40 hrs/week) 1  
 Part time (less than 40 hrs/week) 2
- c) And were you:  
 Employee 1  
 Self employed (your own boss) 2
- d) Were you working more than one job?  
 Yes 1  
 No 2
40. a) Are you currently employed?  
 Yes 1  
 No 2
- b) If yes, are you working:  
 Full time (at least 40 hrs/week) 1  
 Part time (less than 40 hrs/week) 2
- c) Are you an:  
 Employee 1  
 Self employed (your own boss) 2
41. a) Have you changed the number of hours you work per week since you were diagnosed with WG?  
 Yes 1  
 No 2
- b) If yes, was it due to consequences of WG or its treatment?  
 Yes 1  
 No 2
- c) If you held a full time and a part time job before your diagnosis with WG, did you have to give up your part time job?  
 Yes 1  
 No 2

42. a) Since you were first diagnosed with WG, have you had to change your duties at work?  
 Yes 1  
 No 2
- b) If yes, was it due to consequences of WG or its treatment?  
 Yes 1  
 No 2

43. If currently employed, does your employer know you have WG?  
 Yes 1  
 No 2

44. During job interviews, have you ever told the interviewer(s) about your WG?  
 Always 1  
 Sometimes 2  
 Never 3

45. Have you ever been off work for more than 6 consecutive weeks due to WG?  
 Yes 1  
 No 2

46. Have you ever been off work for more than 6 consecutive months due to WG?  
 Yes 1  
 No 2

47. Do you currently have work disability insurance?  
 Yes 1  
 No 2

48. a) Have you ever resigned from a job?  
 Yes 1  
 No 2
- b) If yes, was it related to WG?  
 Yes 1  
 No 2

49. Have you ever lost a job because of WG?  
 Yes 1  
 No 2

50. a) Are you retired from work?  
 Yes 1  
 No 2
- b) If yes, at what age did you retire?  
 — —
- c) Was your retirement influenced by your WG?  
 Yes 1  
 No 2

51. a) Do you receive disability benefits (from any private sources and/or from the VA or Social Security or Workmen's compensation or public assistance)?  
 Yes 1  
 No 2

b) If yes at what age did you start to receive these benefits? — —

- c) If you are currently disabled, what percentage of your previous income do/does your disability payment(s) cover?  
 1-20% 1      60-80% 4  
 20-40% 2      80-100% 5  
 40-60% 3

52. If you are employed full time, how many sick leave days did you take in the last year? — — —

53. If you are employed part time, how many sick leave days did you take in the last year? — — —

54. Please complete the table below for **all** your jobs starting with the year before your WG symptoms started until the present (consider pregnancy as an "other health reason"). Please choose the appropriate number when applicable.

Job Title/Last Salary (Annual)	Start Date	End Date	Full (1) or Part Time (2)	Reason for leaving: WG (3) Other health reason (4) Professional advancement (5) Layoff (6)
A.				
B.				

C.				
D.				
E.				
F.				
G.				

55. If you are currently **not employed**, what is the major reason that you do not work?
- I am still a student 1
  - I am a homemaker 2
  - I am retired 3
  - I do not want to work 4
  - I have been looking for a full time job in the past 2 months, but cannot find a job 5
  - I have been looking for a part time job in the past 2 months, but cannot find a job 6
  - I cannot do any work because of WG or complications of its treatment 7
  - I cannot work in the job I am qualified for because of WG or complications of its treatment 8
  - I receive a disability pension and cannot afford losing health insurance benefits that come with the pension 9
  - I receive a disability pension and cannot afford losing that income 10

In the next section you will find questions regarding your personal finances. This section will help us understand the economic impact of WG (please write clearly).

56. What is the total number of dependents claimed in your last federal tax return? (Please place a check mark in the appropriate blank.)
- |    |     |     |     |
|----|-----|-----|-----|
| 01 | ___ | 06  | ___ |
| 02 | ___ | 07  | ___ |
| 03 | ___ | 08  | ___ |
| 04 | ___ | 09  | ___ |
| 05 | ___ | ≥10 | ___ |

57. What is the total **household** annual income claimed in your most recent federal tax return? (Line 22 of the 1040 form.)  
 \$ \_\_\_\_\_

58. What was your own annual income for the same year from all sources? (See W2 for, bank statements, etc.)  
 \$ \_\_\_\_\_

59. In what tax year did you base the answers for questions 46 and 47?
- |      |   |
|------|---|
| 1994 | 1 |
| 1995 | 2 |

60. a) In the last year, did you lose any income due to WG? Yes 1  
No 2
- b) If you lost personal income, how much income do you think you lost? \$ \_\_\_\_\_
- c) Have you lost income in other years? Yes 1  
No 2
- d) If yes, in how many other years did you lose income? \_\_\_\_\_

61. What was your annual income per year **immediately prior** to your diagnosis of WG? \$ \_\_\_\_\_

62. What was your annual income in the following year? \$ \_\_\_\_\_

63. What was your family-household income in the year **immediately prior** to your diagnosis of WG? \$ \_\_\_\_\_

64. What was your family-household income in the following year? \$ \_\_\_\_\_



72. Do you feel that your illness (WG) has changed your life in a manner that has overall:
- |                        |                                |                              |
|------------------------|--------------------------------|------------------------------|
| a) Affected your mood: | b) Affected your energy level: | c) Your degree of happiness: |
| Better 1               | Better 1                       | Better 1                     |
| No change 2            | No change 2                    | No change 2                  |
| Worse 3                | Worse 3                        | Worse 3                      |
73. Do you have problems with depression due to the consequences of WG or its treatment? Yes 1  
No 2
74. If you have been depressed, do you feel that it was a serious problem before developing WG? Yes 1  
No 2
75. If you have been depressed because of WG, have you sought counseling for help? Yes 1  
No 2
76. Have you felt suicidal because of WG? Yes 1  
No 2
77. Have you ever attempted suicide because of WG? Yes 1  
No 2
78. Do you feel frustrated due to the consequences of WG or its treatment? Yes 1  
No 2
79. a) Are you married? Yes 1      b) If not married, are you divorced (or separated)? Yes 1  
No 2      No 2
- c) If you are divorced, did your WG contribute to the divorce (or separation)? Yes 1  
No 2
80. If married, what effect did the WG have on your relationship with your spouse?
- |                              |   |
|------------------------------|---|
| Made the relationship worse  | 1 |
| Made the relationship better | 2 |
| Had no effect                | 3 |

Additional Comments (please write anything your like):

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Thank you for answering these questions.