

STUDYNAME > 1000 > 001 > F.PNHAA  
Logged as John Doe

QUIT

## Quality of life questionnaire for patients with AA and/or PNH

We would like to know how you have been feeling recently.

Please try to answer as many of the questions as possible by selecting one of the four boxes. Please remember that there are no "right" or "wrong" answers.

Most of the questions are about the past 7 days.

The last two questions are about the last six months.



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QUIT CLEAR ?

## During the past 7 days...

### 1. Have you felt tired?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >



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QUIT CLEAR ?

## During the past 7 days...

### 1. Have you felt tired?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >



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QUIT CLEAR ?

During the past 7 days...

1. Have you felt tired?

Do you confirm you want to skip this question?

CANCEL I CONFIRM

Moderately

A lot

< PREVIOUS

—

NEXT >



## During the past 7 days...

## 1. Have you felt tired?

Not at all

Do you want to quit this questionnaire? If so, all your answers will be saved. Please confirm you want to quit.

[CANCEL](#) [QUIT](#)

A little

Moderately

A lot

&lt; PREVIOUS

—

NEXT &gt;



## During the past 7 days...

### 1. Have you felt tired?

#### Help

Once you have selected an answer:

- Select the **NEXT** button to proceed to the next screen;
- Select the **PREVIOUS** button to proceed to the previous screen;
- Select the **CLEAR** button to clear your answer.

This question is not mandatory. If you are not able to answer or do not want to answer the question, select the **NEXT** button and then confirm you do not want to provide an answer by selecting the **I CONFIRM** button.

You can put the questionnaire on hold by selecting the **QUIT** button at the top of the screen. All your answers will be saved.

To go back to the questionnaire please select the **CLOSE** button.

[CLOSE](#)

A lot

< PREVIOUS

—

NEXT >



During the past 7 days...

2. Have you had to rest?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

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QUIT CLEAR ?

During the past 7 days...

3. Have you been exhausted for days after you exerted yourself?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >



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QUIT CLEAR ?

During the past 7 days...

4. Have you had difficulty getting out of bed in the morning?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >



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QUIT CLEAR ?

During the past 7 days...

5. Has your body felt heavy?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >



During the past 7 days...

6. Has it bothered you that you had to look out for minor symptoms because they could mean something bad?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

STUDYNAME > 1000 > 001 > F.PNHAA  
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QUIT CLEAR ?

During the past 7 days...

7. Have you been short of breath?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >



During the past 7 days...

8. Have you had a tendency to bleed?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

9. Have you had problems with susceptibility to infections?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

10. Have you had problems with swelling or inflammation in your mouth?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

11. Have you had problems sleeping?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

12. Has your everyday life been affected by pain?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

13. Have you had difficulty standing for an extended period?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

14. Has going for a long walk caused you difficulties?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

15. Have you had difficulty climbing stairs?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

16. Have your work or other daily activities been restricted?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

17. Have you had problems coping with household chores?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

18. Has it been a problem for you to ration your strength?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

STUDYNAME > 1000 > 001 > F.PNHAA  
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QUIT CLEAR ?

During the past 7 days...

19. Have you had no energy left for your personal life and hobbies?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

20. Has your normal routine been disrupted?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

21. Have you been unable to bring yourself to do things or have you been apathetic?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

22. Have you found it a problem having to give up sports activities?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

23. Has it bothered you that you were unable to make plans?

Not at all

A little

Moderately

A lot

< PREVIOUS

— — —

NEXT >

During the past 7 days...

24. Has it bothered you that you were unable to be spontaneous?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

25. Has it bothered you that you had to be careful?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

26. Have you had to be careful all the time to avoid catching infections?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

27. Have you had difficulty concentrating?

Not at all

A little

Moderately

A lot

< PREVIOUS

— —

NEXT >

During the past 7 days...

28. Have you been irritable?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

29. Has everything revolved around your illness?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

30. Has it bothered you repeatedly having to cope with your illness?

Not at all

A little

Moderately

A lot

< PREVIOUS

— —

NEXT >

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QUIT CLEAR ?

During the past 7 days...

31. Have you felt that you were missing out on something in life?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

32. Has it bothered you to be classified as ill?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

33. Have you been troubled by thoughts of an uncertain future?

Not at all

A little

Moderately

A lot

< PREVIOUS

— —

NEXT >

During the past 7 days...

34. Has it bothered you that your relatives were upset by your illness?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

35. Has it annoyed you that you had to explain yourself (e.g., why you have been unable to do this or that)?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

36. Have you been afraid of a deterioration in your blood count?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

STUDYNAME > 1000 > 001 > F.PNHAA  
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QUIT CLEAR ?

During the past 7 days...

37. Have you been bothered by your blood count results?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

38. Have you been afraid that therapies might not work?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

39. Have you been concerned that there might not be any more therapy for you?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

40. Have you been afraid of a relapse or deterioration?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

41. Have you had signs (e.g., pallor, bruises, dark urine, yellow skin) that repeatedly reminded you of your illness?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

42. Have you felt vulnerable?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

43. Have you felt at the mercy of your illness?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

44. Have you worried a lot?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

45. Have you felt depressed?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

STUDYNAME > 1000 > 001 > F.PNHAA  
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QUIT CLEAR ?

During the past 7 days...

46. Has the illness made you feel less attractive?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

47. Have you been less interested in sex?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

48. Have you been less able to enjoy sex?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

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QUIT CLEAR ?

During the past 7 days...

49. Have you felt good about your body?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

50. Have you been able to do what you wanted?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

51. Have you been proud of what you achieved despite the illness?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 7 days...

52. Have you felt supported by friends and family?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 6 months...

53. Have you still been able to go on vacation as you wished?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

During the past 6 months...

54. Have you missed the interaction with other patients?

Not at all

A little

Moderately

A lot

< PREVIOUS

—

NEXT >

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QUIT

Thank you for completing the questionnaire.

If you want to review or change your answers, please select the **PREVIOUS** button below.

Once you select the **FINISH** button you will no longer be able to review or change your answers.

*Please note: If you are having any severe symptoms, health issues or other concerns, please be sure to discuss these with your doctor or nurse. The answers you provide to the questions are not being directly shared with the members of your healthcare team.*

&lt; PREVIOUS

FINISH &gt;



STUDYNAME > 1000 > 001 > Questionnaire completed

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Thank you! You have completed all the questionnaires.

EXIT





**Technical information**  
*this screen will not be displayed*

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