

NONF Needs

This survey is designed to help us further develop NONF and address the issues that are important to you.

Medical Research

1. How important is it to you that NONF to provide information about current medical research for ON?
 not at all important somewhat important very important

2. How important is it to you that NONF to provide information about clinical trials that you could join?
 not at all important somewhat important very important

3. Do you understand the medical information about ON that is presented on this website?
 No Yes
If no, please specify what you do not understand _____

4. What specific medical aspects of ON would you like more information?

ON Treating Physician Information

5. How important is it to you that NONF to develop a nationwide list of physicians specializing in ON?
 not at all important somewhat important very important

6. How important is it to you that NONF to provide these physicians' contact information?
 not at all important somewhat important very important

7. How important is it to you that NONF to provide a list of these physicians' publications/research activities?
 not at all important somewhat important very important

8. What other information about physicians who treat ON would you like to know?

Patient Services (check all that apply)

9. Would you be interested in professional advice on the following topics?

- Nutrition
- Exercise
- How to talk to your doctor
- How to talk to your employer
- Physical therapy
- Assistive devices (canes, crutches, wheelchairs, etc.)
- Care/family support
- Pain management
- Treatment options and outcome data

10. What would you like to see on the NONF website? (check all that apply)

- Be able to tell your story and read other patient stories
- Osteonecrosis jokes and fun
- National Osteonecrosis Foundation store
- Provide links to egroups that provide communication with other patients (i.e. chatroom, blog)
- Look for advice and/or offer advice to other ON patients
- Learn about obtaining disability benefits
- Find financial aid
- Ask a doctor a question about your ON
- Volunteering for NONF
- Osteonecrosis advocacy: Please specify _____
- Osteonecrosis events

- Donating money to NONF
 - Quarterly Newsletter
 - Other _____
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About You

11. Age: under 20 21-30 31-40 41-50 51-60 61-70 71 or older
12. Sex: Male Female
13. Total number of joints affected: _____
14. Joints affected: hip(s) knee(s) shoulder(s) ankle(s) elbow(s) jaw other _____
15. Working status:
 full time part time unemployed by choice unemployed (looking) unable to work
16. How did you hear about NONF?
 web search doctor family/friend support group other _____
17. Is there any other information or services not mentioned that you would like to see NONF provide?

NONF Membership

18. When you joined NONF what did you expect your membership to provide? _____
19. What do you believe the most important function of NONF is? _____
20. What has NONF done the best in meeting your expectations? _____
21. What do you think NONF needs to improve? _____
22. After you receive treatment for your ON, how likely are you to maintain interest in ON-related issues?
 not likely somewhat likely very likely
23. What, if any, are the issues important to you that have not been mentioned in this survey? _____

Thank you for participating in this survey. We will try our best to meet your ON needs. Please send an email to nicole.willis@gmail.com with any suggestions to develop NONF or the NONF website that have not been mentioned in this survey. Thanks again.