

Alpha-1 center initial patient visit

Welcome to the Boston Medical Center/Boston University Alpha-1 Clinical Center. While you are waiting for your Doctor, please fill out the questionnaire below to help us take care of you. If you do not know the answer to any question or prefer not to answer it please write the words not sure or leave the answer blank.

1. What would you like out of today's visit.
2. Do you know if you have a diagnosis of alpha-1 antitrypsin deficiency? How was the diagnosis made? Do you know your genotype or phenotype alpha-1 test result (e.g. PiZZ, SS, SZ, MZ, MM other, don't worry if you don't know what this question means—we will explain) If you know this test result, on what date was this test done?
3. Do you have lung or liver disease, both, or don't know?
4. Are you now or have you ever been on “augmentation therapy” for Alpha-1?
5. Does anyone in your family have liver or lung disease? Provide as much detail as possible. Use the words maternal or paternal to indicate whether relatives or grandparents are on your mothers or fathers side respectively.
6. Are you a smoker or have you ever smoked cigarettes? How old were you when you started or stopped and how many packs a day did you or do you smoke?
7. Have you been seen by a pulmonologist or liver specialist? Who? Please list their phone number if you have it.
8. Who do you consider to be your primary care physician? Do you want us to send a copy of RN notes to this person? Or to any other physicians? Please list names and addresses of all those you wish to have copies of your notes.
9. Does anyone else in your family have known Alpha 1?
10. Please summarize your lung or liver disease history beginning with your childhood. For example did you have a healthy childhood at what age did you 1st develop any problems what were these problems?
11. Do you now or have you ever worn oxygen? how many liters per minute and what type of delivery device?
12. Do you know if you had jaundice as a baby? Do you know if you were normal term delivery?
13. Do you know if you have IGA deficiency?

14. Do you know if you have been vaccinated against influenza, pneumococcus, or hepatitis B? When were you last vaccinated?
15. What medications do you currently take?
16. Do you have any known allergies to any medications; what reactions do you get?
17. Please list your other known medical problems.
18. Have you ever been exposed to tuberculosis? Have you ever had a skin test for TB and what were the results? When were these tests done approximately?
19. Are you interested in having your family members tested for Alpha-1 or genetically counseled?
20. Have you suffered from depression as a result of alpha-1? Are you interested in meeting with a counselor or psychologist?
21. If you smoke are you interested in a smoking cessation program or quitting?
22. What do you do for work? Did you ever work in a factory, Naval shipyard, or participate in demolition work?
23. Have you ever been exposed to asbestos as far as you know? When and where? Do you have other occupational exposures to fumes dusts or toxic inhalations?
24. Do you know where your ancestors come from? For example Ireland or northern Europe?
25. Have you ever had a chest x-ray or chest CAT scan? Please bring in a copy of your most recent scan or films.
26. Have you ever had liver function testing? When? Do you know if they were normal or abnormal?
27. Have you ever had pulmonary function tests? Please bring in a copy of your results if possible. When were these tests performed? Do you know if these were normal or abnormal?
28. Have you ever used inhalers do you feel these inhalers help you and which ones help?
29. Do you drink alcohol? How much?
30. Do you take any illicit drugs either inhaled injected or in pill form? Please leave blank if you prefer to discuss in person.