

- If on oxygen, bring your oxygen and any tests such as oximetry or arterial blood gases (ABGs)

Be sure to tell the doctor about any recent...

- Hospital or emergency room visits
- Times you've been on antibiotics or steroids (such as prednisone)
- Times you had a worsening of your lung problems
- Any other new or additional medical problems

Need Help Getting There?

The Alpha-1 Foundation offers a travel stipend to help Alphas around the country visit a Clinical Resource Center (CRC). To qualify, Alphas must be newly diagnosed or have never visited a CRC.

To request help with travel costs, contact the Alpha-1 Foundation CRC Access Program at accesscrc@alpha1.org, or call 877-228-7321.

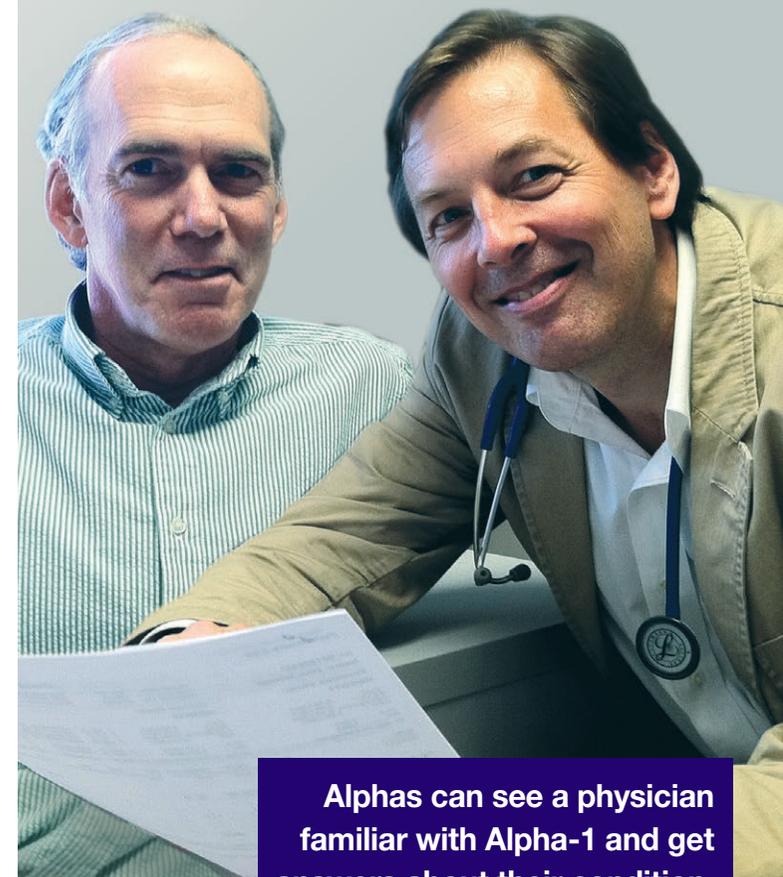
ON THE COVER: Charlie Strange, MD, director of the Alpha-1 Foundation Research Registry at the Medical University of South Carolina, reviews medical information with Alpha Bill Zink.



The Alpha-1 Foundation is committed to finding a cure for Alpha-1 Antitrypsin Deficiency and to improving the lives of people affected by Alpha-1 worldwide.

www.alpha1.org
 1 (877) 2 CURE A1 | 1 (877) 228.7321
 3300 Ponce de Leon Blvd.
 Coral Gables, FL 33134

Alpha-1 Foundation Clinical Resource Centers How to Find an Alpha Doc



Alphas can see a physician familiar with Alpha-1 and get answers about their condition.



How to Find an Alpha Doc

Clinical Resource Centers (CRCs) are located throughout North America and specialize in patient care, education and research for those with Alpha-1 Antitrypsin Deficiency (Alpha-1). Some centers treat lung disease and others treat liver disease. Many have other resources for Alphas, such as support groups, pulmonary rehabilitation and organ transplant programs.

At a CRC, Alphas can see a physician familiar with Alpha-1 and get answers about their condition. They can also find out more about how Alpha-1 affects their families and learn about the testing choices available to family members. Each center must meet certain criteria in order to be listed as a CRC through the Foundation.

Why visit a CRC?

For many Alphas, it can be a challenge to find a doctor who is knowledgeable about Alpha-1. In this common situation, a visit to a CRC can be a consultation with a doctor who is:

- Knowledgeable about Alpha-1 lung or liver disease
- Current on the latest research and treatment
- Experienced in treating and supporting Alphas and the Alpha-1 community
- Able to help educate both Alphas and their families.

What about my current doctor?

A visit to a specialist can be helpful to both you and your current physician. Seeing an “Alpha Doc” does not change the relationship you have with your current doctor. With your permission, any or all of your medical information can be shared with your physician of choice. Be sure the CRC office has the name, address and phone number of your local physician.

Where can I find an Alpha Doc?

Find an Alpha Doc at the Alpha-1 Foundation website, www.alpha1.org. Click on “Clinical Resource Centers” or “Find an Alpha Doc”. You may also call the Foundation at 877-228-7321 for more information.

Contact the center nearest you for information or an appointment. When you call, please tell the doctor or the person you speak with in the doctor’s office that the Alpha-1 Foundation Clinical Resource Center Program referred you.

How will my visit be paid?

Medicare/Medicaid and private health insurance cover most services provided by CRCs. Be sure to check your coverage with your insurer and ask about your responsibilities for referrals, co-pays and deductibles.

Know before you go!

Questions you might want to ask

Your visit should be a two-way discussion of your condition and the treatment that’s right for you. Here are some suggested questions you might want to ask the doctor:

- What are my treatment options?
- How often should I schedule follow-up visits?
- What changes can I expect?
- Will I need additional tests?
- Should my family be tested?
- How can my family be tested?
- What can I do to take care of myself?

What should I bring to my appointment?

Some things to bring, or have sent in advance of your CRC visit:

- Your Alpha-1 test results and any other medical test results that may be helpful
- A list of current medications. Even better, bring all your medications with you to your visit. If you’re on augmentation therapy, bring your dosing information.
- All lung function tests, CT scans or X-rays
- Insurance information
- Ask if you may bring other family members on your visit.

