Transcript Details

This is a transcript of an educational program. Details about the program and additional media formats for the program are accessible by visiting: https://reachmd.com/programs/clinicians-roundtable/increase-alpha-1-antitrypsin-deficiency-testing/49233/

ReachMD

www.reachmd.com
info@reachmd.com
(866) 423-7849

How to Increase Testing Rates for Alpha-1 Antitrypsin Deficiency

Announcer:

You're listening to *Clinician's Roundtable* on ReachMD, and this episode is sponsored by Grifols. Here's your host, Dr. Brian McDonough.

Dr. McDonough:

This is *Clinician's Roundtable* on ReachMD, and I'm Dr. Brian McDonough. Joining me to share some practical, real-world strategies for increasing testing rates for alpha-1 antitrypsin deficiency is Dr. Brooks Kuhn. He's an Associate Professor of Medicine and the Medical Director of the Pulmonary Faculty Practice at UC Davis Medical Center. Dr. Kuhn, welcome to the program.

Dr. Kuhn:

Real pleasure to be here, Brian. Thank you for having me.

Dr. McDonough:

So why don't we start with some context, Dr. Kuhn. Even though current guidelines recommend testing for alpha-1 antitrypsin deficiency in patients with COPD and other high-risk features, screening rates remain low. In your experience, why is it challenging to incorporate these recommendations into routine clinical practice?

Dr. Kuhn:

That's a phenomenal question here. I can tell you it's not because there haven't been efforts in this by the Alpha Foundation. People have been trying for a long time to try and increase detection. The turn of phrase that we say is: "it's not a rare disease; it's a rarely identified disease." So much so that in 2003, the ATS guidelines set a very broad criteria for getting tested. Anyone with obstruction, anyone with emphysema, and anyone with chronic bronchitis should get tested. Yet, despite this really broad criteria for testing, only about 10 percent of people with alpha-1 have probably been detected in the United States.

So to really get the core of your question of why this is happening, I think there's a lot of different factors at play. The first one is just from a busy clinician myself, and my wife is actually a primary care doctor. And every time I pull her ear talking about alpha-1 and about how she should test her patients, she's like, 'yep, Brooks great, absolutely.' But then she's busy in practice, and her patients come in and they've got heart disease, blood pressure, or seven other medical problems that need addressing. And then, oh, by the way, there's the obstruction on the PFTs, right? That's not really a salient problem, so it can march down the priority list pretty frequently. Not to mention all of us have a hard time when there's this deluge of new information that we're getting in medicine—new therapies in heart, lung, and cancer—there's a never-ending flow of education. So it is a rare disease, and to be honest, we have an uphill battle in just getting the attention.

There are many other factors that play into why this isn't going on here. And frankly, one of them that's a challenge is a little bit of therapeutic nihilism. The thought of, 'gosh, okay, they've got COPD, what am I going to do differently?' And I have really three things that I think are majorly different once you call someone with COPD and alpha-1. First, smoking cessations. 50 percent are more likely to quit smoking. If you have a diagnosis of alpha-1 and if you compare that to if you don't, that's huge. Secondly, we do have augmentation therapy. And third, it's a genetic disease. All of us have kids, grandkids, families, aunts, and uncles. So really, once you unravel an entire family, maybe it won't impact that one patient you identify as a carrier, but gosh, it could really have a huge impact for the entire family.

Dr. McDonough:

Given those challenges, how can tools like EHR prompts, order sets, or risk-based algorithms help standardize testing at the point of

© 2026 ReachMD

care?

Dr. Kuhn:
That's a great question here, and I've got to give you my bias as a technophile here. I really think that's going to be a large part of our solution moving forward. Because we're all such busy clinicians and only getting busier, we need tools from the EHR that aren't just going to add more for us to do. We need tools that make it easier for us to do the right thing.

Examples in my clinic here that we use are we have an order set for the "COPD labs." So I want an eosinophil count, PFTs, high-res CT scan of the chest, and alpha-1 testing. So when I'm proselytizing to my fellows and saying, "Hey, we need to work up for COPD," they don't have to remember alpha-1. They have to remember my order set that I want. We did the same thing on patients admitted to the hospital with a diagnosis of COPD. We just did the simple thing of, again, the standard admission order set for all the patients here, and there's alpha-1 and the box is pre-checked. So if they don't want to check for alpha-1, they have to unclick that bottom, right? So that gentle little nudge just makes the right thing to do easy. They don't have to think, they don't have to dig deeper, and they don't have to pull up those slides from when someone came to give them education about it. It's right there in front of reminding them to do it.

Dr. McDonough:
For those just tuning in, this is *Clinician's Roundtable* on ReachMD. I'm Dr. Brian McDonough and I'm speaking with Dr. Brooks Kuhn about how we can improve testing rates for alpha-1 antitrypsin deficiency.

Now let's take a look at some of those tools and other models in the real world. In a community-based study, a multimodal intervention that combined provider education, EHR prompts, and simplified testing workflows led to a significant increase in adherence to screening recommendations. From your perspective, Dr. Kuhn, what makes this type of multifactorial approach so effective?

Dr. Kuhn:
I know the publication you're referring to here, Brian, and what struck me when I read that was that it wasn't just a one-off. Here's a single intervention as we are inclined to do in science, right? One intervention, and we'll see what happens. They just said, let's make alpha-1 easy, and do stem-to-stern intervention here to really make the testing easy and make follow-up and education for the clinician so they have the education to interpret that data pretty easy, and that really leads to sustainability. When you really truly build systems around not just one-off education, that's when you can really make it easy for groups and make the bar lower.

I think all of us clinicians want to do the right thing for our patients. We all want to do the best absolute care. So having a multimodal system like the one you mentioned here makes it easy for that person at the point of care. It's just like, 'ah, great. I got the system test here. I got a system for follow-up to make sure my clinician staff quickly responds to it here, and then subsequently, I know how to interpret it here; I have resources for that as well.'

Dr. McDonough:
And other health systems have used electronic medical records to identify patients with COPD and engage with them through digital messaging to encourage testing. While uptake was modest, this approach did result in a meaningful detection rate among those who completed testing. So how do you see these digital, patient-directed approaches fitting into clinical practice? I know you've addressed it a bit.

Dr. Kuhn:
I think this is a great view here again. I think the classic paradigm of the doctor-patient relationship is the doctor-patient right in front of each other, right? I think as systems grow bigger, more complex, and with more demands, we need this population view. Really, population health is what I'm referring to. Owning the entire group of people with airway disease or liver disease—people at risk. And then saying, 'alright, who in there needs to really get tested?'

Another adage I can steal from the alpha space here is we always say "you need to rule it out and not rule it in," right? You shouldn't wait until someone comes in with crippling lung disease or their FEV one's low and they've never touched a cigarette. You don't want to wait for them and say, 'maybe we should see if there's a genetic driver.' You want to look at a large population and people at risk and theoretically catch them early. Identify them early; take the bullet out of the gun and not wait for the exit wounds.

So I really have a lot of hope, especially with new AI tools that are coming that are able to better analyze, maybe even beyond the predictors that we know for risk and likelihood of having alpha-1 so that we can not just identify these patients, but also take it off from just saying the clinician, primary care, or pulmonologist should be doing this work here. As a health system, we should readily take ownership, and I think this is great that we leverage data tools to really do this.

Dr. McDonough:
If we examine one more approach in action, a large screening program in Germany combined awareness efforts with free, mail-in

diagnostic testing for more than a decade. Among the nearly 19,000 individuals tested, about 10 percent were found to have severe alpha-1 antitrypsin deficiency. What do these findings tell us about the value of targeted screening and reducing barriers like cost in improving detection?

Dr. Kuhn:
Well, first off, it sounds like that we got a theme that the Germans are doing great, so we got to do a little catch up first. But just from a system standpoint here, the real power is looking in this large group of cohort and actually having direct-to-consumer advertisement for testing. So a lot of patients were old school; they were only getting data from their clinician. Nowadays, patients are online, they're educated, and they're looking at the COPD Foundation website and the Alpha-1 Foundation website. So in my view, the more we can lower the bar for testing and make it easier for the patient themselves to actually get testing, the better.

There are efforts in the United States by the Alpha-1 Foundation through a group that they're supporting called Alpha Detect, where it's really trying to support free anonymous testing for patients and health systems. So they can get testing taken care of because cost is another thing that comes up when you start throwing around genetic testing. So that's another opportunity where we can lower the bar to make it easier to do the right thing here.

Dr. McDonough:
Finally, Dr. Kuhn, let's take a look at the big picture here. What operational factors influence whether screening programs are successful and sustainable in practice, and how can we address them?

Dr. Kuhn:
That's another great question here, and as much as I want to give you the answer with some technology or approach, the core thing for any system's success is a champion. It's someone who's going to be there to really launch it with passion. And more importantly, someone who's going to be there in the long run to iterate on the process and really remind all of us clinicians about the importance of this.

You know, Brian, if your EHR is anything similar to mine, there is a graveyard of order sets and tools that are well-meaning and are probably actually great tools, but they never get used so they really have no use. So you really need a person who's going to make sure that whether it's just in the ears of their colleagues or gentle reminders in the EHR emails, they're looking at actual data on testing for alpha-1. You need someone there who's going to really be that person.

The second thing is, in general, you need a system that takes the weight off of the clinician. Beyond alpha-1, as clinicians, we keep taking more on our shoulders. We keep saying, 'we'll add more, we'll take care of those inboxes, and we'll take care of taking those orders.' Yes, we can, but honestly, we got to start looking the other way. We got to start advocating for ourselves by saying we need a system so that we can be the ones who choose the clinical decision. We need a system that's going to help make the testing get done here so I'm not going to have to do finger prick or anything like that. We're going to have to make a system that follows it up and maybe even sends the patient education if there's anything abnormal before I even have a chance to look in my inbox. And we need to have a system to make the interpretation and everything on the backend easy and friction free. So really, if it doesn't take weight off of the busy clinician, it's not going to be sustainable. It's going to end up in that graveyard.

Dr. McDonough:
As those final thoughts bring us to the end of today's program, I want to thank my guest, Dr. Brooks Kuhn, for joining me to share these real-world strategies for improving adherence to alpha-1 antitrypsin deficiency screening recommendations. Dr. Kuhn, thanks so much for being here today.

Dr. Kuhn:
It's been a pleasure, Brian. Thank you.

Announcer:
This episode of *Clinician's Roundtable* was sponsored by Grifols. To access this and other episodes in our series, visit *Clinician's Roundtable* on ReachMD.com, where you can Be Part of the Knowledge. Thanks for listening!

© 2026 ReachMD