How many pulmonologists is too many? As many as you need to find a right one!

Several callers described a process of finding the right doctor, some had seen 3, 4 even 6 pulmonologists until they found the doctor who understood how to treat them. This process can take years, with costs of time (waitlists for new doctors), energy, money, fatigue of travel to new locations, the headache and logistics obtaining and maintaining your medical records. Participants on the call described the frustration of physicians attempting new treatments without confidence, preferring physicians to be honest in saying, “I just don’t know what’s wrong with you.” We discussed how the right provider will offer:
- Good communication
- Help you feel comfortable calling as needed, asking questions
- Be willing to try new things as new information becomes available
- Establish a trusting partnership (especially for patients who are well informed about their illness)
- Recognize [you] as a person, not just a patient

Even with the best provider, callers agreed that patients need to be their own advocates. It is important to be proactive in the management of your own illness, documenting episodes of illness, treatment and responses. (RESOURCE: The AARP has forms on-line for how to prepare for a doctor’s visit).

Pitfalls in Doctor/Patient Relationships
- The doctor who becomes accusatory when treatment is not going well on a regimen the doctor thinks should work.
- Disagreement over course of treatment
• A patient presents research and the doctor feels threatened. Callers agreed that the process of building relationship with new providers can be overwhelming and exhausting, and it can be hard to stay optimistic.

Managing Multiple Providers
It can be a challenge to manage different providers who may have different recommendations (e.g. a local pulmonologist vs. a consulting pulmonologist, a pulmonologist vs. PCP). Callers discussed:
• Choosing a doctor to follow
• Communicating proactively, ask one doctor to call another—they may do so even if they do not volunteer to do so up front
• Ask if email communications would be welcome