Lesser Known Ways to Get Involved in Clinical Asthma Research

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Asthma and Research

Have you or a loved one been diagnosed with asthma? Would you like to get involved in research studies without testing a new procedure or an experimental drug? Very few people know about the Patient Representative Program, a program that helps you participate in the decisions made by FDA regarding new, or already approved drugs and devices. Let’s see how you can bring your voice to drug and device approval and safety.

About Patient Representatives

You can participate in this program in several ways. For example, you can be part of an advisory committee; this position allows you to ask questions and provide comments and feedback to help the committee make certain recommendations. Meetings are held in Washington, DC and the FDA pays a salary for your time spent in meetings, as well as travel expenses if the distance between your home and the meeting place is more than 50 miles. You could also act as a consultant for scientists and doctors who review the risks and benefits of certain medical products. Another option is to become a presenter at meetings and workshops on Asthma and various health policies conducted by the FDA.

If you don’t have a special background in science or research, don’t worry. You need to have general knowledge of the disease and the ability to understand and talk about scientific data. The FDA wants to hear your opinion, as an asthma sufferer or as a caregiver for an asthma patient.

How to Become a Patient Representative

You must meet the criteria; based on whether or not you meet the criteria, you may be selected to be a Patient Representative. Firstly you must be eighteen years of age or older, and be a legal U.S citizen. Secondly, you need to have experience with asthma, either as a patient or a primary caregiver for someone diagnosed with the condition.

You also need to posses the ability to be objective; you will be representing the concerns of other people diagnosed with asthma. You have to be willing to speak on their behalf and express their views, understand various treatment options for asthma and research conducted in this area, and you cannot have financial conflicts of interest. For example, you can’t participate if you own stocks in companies that can be influenced by the FDA’s decisions.

The Next Step

Next, you’ll fill out a Patient Representative form and submit it to the the FDA; The Patient Network Program.

Patient representatives are recruited as needed to help advise the FDA on various drugs, devices and biological agents that are in the process of being approved, or to provide your opinion on product development and review

process. Currently, the FDA is looking for patient representatives for asthma, both pediatric and adult, as well as other conditions such as stroke and heart diseases.

Being a Patient Representative

Once you become a patient representative, the FDA staff will train you and help you better understand the necessary policies, procedures and regulations. You will participate in teleconferences, webinars, and annual conferences and receive one-on-one support as needed.