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## Things Vasculitis Patients Want their Pulmonologists to Know



- 1 On paper we may look good, but we are struggling to breathe. Please take us seriously when we say we are having shortness of breath, regardless of what the tests show.
- 2 The fatigue is impossible to describe. We know exercise is important, but it is hard to exercise because of the pain, low stamina, and extreme fatigue.
- 3 Lungs don't exist in a vacuum. Listen to all of our symptoms.
- 4 Successful treatment of vasculitis requires a team approach. Coordinating care and treatment with other medical professionals such as rheumatologists and nephrologists is essential.
- 5 Prompt diagnosis and early treatment is a game changer for patients.
- 6 Please educate us. Things that might seem common knowledge to you, such as the side-effects of glucocorticoids or the importance of deep breathing for lung health, might be unfamiliar to us.
- 7 The pain is real and can be debilitating. For many of us it hurts when we sneeze, cough, yawn, or take a deep breath. Pain relievers are often not very effective.
- 8 If we have lower respiratory issues related to the vasculitis we will often have upper respiratory issues as well and vice versa. We may need treatments that address both lungs and sinuses in order to breathe more freely.
- 9 If you suspect we have eosinophilic asthma, please evaluate for the possibility of EGPA.
- 10 Regularly monitor our pulmonary health. Vasculitis is chronic and incurable and the damage to our lungs increases over time.
- 11 Ensure your patients are connected with the Vasculitis Foundation for education and support resources.

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