

Patient voice

Patient testimony: hyper-IgE syndrome and associated lung infections

Sandra Hicks summarises her experience with hyper-IgE syndrome (HIES), a primary immunodeficiency syndrome, and how living with this rare genetic condition and associated lung infections impacts her life (video S1). As a direct consequence of HIES and its effect on the immune cascade, Sandra concurrently manages chronic *Aspergillus* infection (aspergillosis), nontuberculous mycobacterial infection (*Mycobacterium avium-intracellulare*), bronchiectasis colonised with *Pseudomonas* and asthma. She discusses the effect this rare disease and infection burden have on her daily life, including the influence of other factors such as temperature, humidity and antimicrobial resistance.

Sandra conveys her hopes for clinicians treating others with similar disease profiles, including the impact of immunoglobulin treatment; early,

accurate diagnosis of primary immunodeficiencies and fungal infections; and awareness of potential interactions between antifungals and other medication (<https://antifungalinteractions.org>). She also discusses the importance of comprehensive, timely communication within and between multidisciplinary teams. Finally, Sandra emphasises the value of support from allied healthcare professionals for people with chronic lung conditions.

Sandra has since returned to pulmonary rehabilitation classes. These provide great benefit, not just for people with COPD but also for those living with other lung conditions. Making this service widely accessible would improve management of chronic lung conditions and could even reduce associated healthcare costs.

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Conflict of interest:

S. Hicks disclosure statement is included in video S1. R. Orritt was an employee of the European Lung Foundation at the time of writing.

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Living with hyper-IgE syndrome is particularly challenging because of associated respiratory infections. Healthcare professionals could help patients by working towards early, accurate diagnosis of primary immunodeficiencies and fungal infections. <http://bit.ly/36qLbgz>



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