

Wednesday 5th February 2025

Dear [name],

We are writing to you as a collective of patient and expert representatives to draw your attention to the challenges facing vitiligo patients across the UK and the inequalities experienced by this community. There are currently no licensed treatments for vitiligo available through the NHS, and we were very disappointed that NICE previously rejected ruxolitinib cream at a second NICE Appraisal Committee Meeting (ACM) earlier this year. Whilst we welcome the fact that a formal patient-led appeal has recommended a third ACM, we are concerned this may yield the same results and we are calling on NICE, NHSE, the Government and the drug manufacturer to come together to explore all options to enable timely and equitable patient access.

The patient community (The Vitiligo Society & Vitiligo Support UK) and The British Association of Dermatologists have appealed against the decision taken by NICE in relation to their appraisal of ruxolitinib cream for treating non-segmental vitiligo in people over 12 years. We were concerned that their decision did not sufficiently consider the patient voice, the severe impact of the condition and the inequalities that exist for vitiligo patients. We were pleased that three of the appeal points were upheld at appeal and that a third ACM will now take place. However, we remain concerned that without further commercial negotiation and flexibility we again risk a scenario where UK patients will not be able to access the first vitiligo treatment breakthrough, when it has already been deemed cost-effective in countries across Europe.

We understand that there have already been conversations around agreeing a complex patient access scheme and that it is at the discretion of NHS England to consider this as part of negotiations. We believe it is crucial that all avenues are explored as part of these ongoing processes and that there is continued dialogue so that patients do not miss out on what represents the first treatment innovation for this condition.

To highlight why we feel so passionately about this, we wanted to set out the impact of vitiligo, the inequalities that exist across the UK and the importance of new innovations for the estimated one million people living with vitiligo in the UK.

As you may be aware, vitiligo is a chronic autoimmune disease leading to a loss of pigmentation in the skin. It is widely considered to have psychologically devastating effects, as it challenges societal norms related to skin pigmentation across various cultures. Recent research by The Vitiligo Society discovered that 80% of patients said vitiligo negatively impacts their appearance and almost half (46%) have suffered feelings of isolation and depression. However, anyone, regardless of their demographic, or the extent of their vitiligo, has the potential to struggle significantly with this disease, with young people and people with darker skin most likely to feel these effects.

Despite the extreme social and psychological effects vitiligo has, research shows that a staggering 60% of patients do not treat their vitiligo due to the lack of effective treatment options available on the NHS. One patient described navigating the current unlicensed treatments as a “lengthy trial and error process” that was “more damaging to my mental health than it was successful in treating my vitiligo”.

This is the last point in the appraisal process where we can make any impact on the outcome, and we need those with influence to speak on behalf of these patients, who for so long have felt dismissed and unheard. Often these appraisals can seem remote from the needs and perspectives of patients, so we wanted to leave with you a message received by The Vitiligo Society following the NICE announcement not to recommend ruxolitinib cream:

***“The one tiny bit of hope that only just kept me going has gone. [I] can't do it anymore, there is nothing positive now.”***

We ask on behalf of all patients, on behalf of individuals protected by equality legislation, and all the appellants involved in the process, that you do everything within your power to influence this process and help vitiligo patients get access to a treatment that they so desperately need.

We look forward to hearing from you.  
Yours faithfully,

**Abigail Hurrell**, Charity Director of The Vitiligo Society  
**Heather Blake**, Chief Executive of Changing Faces  
**Emma Rush**, Chief Executive of Vitiligo Support UK  
**Prof David J Gawkrödger MD FRCP**, Chair of Medical and Scientific Board, The Vitiligo Society  
**Dr John Ferguson**, Consultant Dermatologist, St John's Institute of Dermatology at Guy's and St Thomas' Hospital  
**Prof Anthony Bewley BA FRCP**, Consultant Dermatologist, Barts Health NHS Trust  
**Prof Viktoria Eleftheriadou MD MRCP(UK) SCE(Derm) PhD**, Consultant Dermatologist & Lead for the Vitiligo Clinic and Research at Walsall Healthcare & The Royal Wolverhampton NHS Trust  
**Prof Eugene Healy PhD FRCP FRSB FAoP**, Professor of Dermatology or University of Southampton & Honorary Consultant Dermatologist at the University Hospital Southampton NHS Foundation Trust