

31st August 2024

Rebecca Geohagen
10 Dunston Street
Openshaw
Manchester
M11 2JU

Dear Ms Powell,

I'm writing to you today to express my concern about unsafe practices surrounding the prescribing of topical steroids in the UK. In its joint position statement of January 2021, The National Eczema Society and the British Association of Dermatologists acknowledge that *"adverse effects can result from daily use of high-strength TCS over a long period...These effects are sometimes referred to as Red Skin Syndrome, Topical Steroid Addiction or alternatively Topical Steroid Withdrawal (TSW) syndrome"*. This is associated with *"rapidly worsening redness, soreness, itch, scaling, and swollen glands"*. Other severe symptoms commonly described by patients are: burning painful skin, swelling, extreme shedding, oozing, nerve pain, hair loss and insomnia. This causes sufferers to become extremely ill, lose their independence, experience a reduced quality of life, struggle to remain in education or employment, and suffer from severe mental health problems.

Yet despite this, topical steroids are prescribed injudiciously, with inconsistent instructions from prescriber to prescriber and no limit on how long they can be prescribed for. They are often put on repeat prescription, without any routine monitoring or follow up, and can therefore be accessed continuously by patients who are unaware of the dangers of prolonged use.

This issue is extremely important to me because I have been suffering from Topical Steroid Withdrawal Syndrome for the past 4 years. In 2019, I took a trip to Jamaica and after suffering from a minor allergic reaction, I was prescribed 2 potent doses of steroids which were both injected and orally administered. Shortly after my return to England, I began to show signs of symptoms of something that I had never experienced before, Topical Steroid Withdrawal (commonly known as TSW). At first I believed that this was just a small bout of eczema and after moving to Manchester this became extremely worse.

I moved to Manchester after consulting for a number of years in my field of compliance and anti-money laundering which I thoroughly enjoyed. However I felt like I wanted to pursue something more fulfilling, so I began the journey to starting up my own business. Unfortunately, my endeavors soon halted as my condition worsened. After suffering for a considerable amount of time, trying to understand why my skin felt as though it was constantly on, I consulted the GP and was assigned a dermatologist.

My GP in and Dermatologist at Basildon hospital never gave me sufficient usage instructions and prescribed me steroids continuously for 1.5 years, which I used when an eczema flareup was happening which got increasingly more frequent as I used the steroids. This has had a massive impact on not only how I live my daily life but also my mental health. For the past 5 months I have not been able to have enjoy life to the same quality that I did before Topical Steroid Withdrawal. I am also in my second year of university and this had an immense impact on my studies and also, at times, has threatened my ability to finish the course, causing a lot of stress. I have also attended relentless doctors appointments where I have been made to feel insignificant and belittled by medical professionals who did not believe me and therefore 'forced' using steroids upon me trying to scare me into using them, even when I refused. I feel as though I have lost 5 months of my life to this condition and this is one of the milder cases, there are many more people who have lost multiple years of their life due to the negligence of doctors and dermatologists.

The attitude of clinicians when a patient raises the prospect of TSW is, unfortunately, akin to the attitudes so strongly condemned in the recent Baroness Cumberlege report 'First Do No Harm'.² Although the three situations which comprised that review (Primodos, sodium valproate and pelvic mesh) differ from TSW, there are a number of important and striking parallels:

- the Cumberlege report is all about people who have suffered avoidable harm
- the patient groups were found to be well informed, knowledgeable, and research based
- the healthcare system was found to be "not good enough at spotting trends in practice and outcomes that give rise to safety concerns. Listening to patients is pivotal to that". It was also noted that "And, while we have looked in detail at only three interventions, we have heard nothing that would lead us to believe that things are different for other surgical procedures and devices or other medications"

One particular statement resonates very strongly:

"...These patients should not have to campaign for years or even decades for their voices to be heard. Patients should not have to find the evidence to say whether the treatments they are being offered are safe and will leave them better off than before. They should not have to join the dots of patient safety. But when they do just that, they deserve to be listened to with respect."

TSW sufferers have been 'joining the dots' for years and it is in everyone's interests (but most of all in the patients') to conduct proper research into the extent and gravity of this condition. A review similar to 'First Do No Harm' for TSW would be very useful – without patients having to fight for years on end for this to happen.

Many TSW 'Warriors' have now reported these severe side effects and the MHRA are now actively working on a wording to be included in the SmPC and PIL of all topical steroid products with a view to subsequently raising awareness through their Drug Safety Update publication

I would like you to campaign to:

- Get Topical Steroid Withdrawal Syndrome officially recognised by the NHS so that prescribers can be trained in how to recognise and treat it;
- Get TSW on the agenda of the All Party Parliamentary Groups: 'Skin' and 'Prescribed Drug Dependence' (the scope of both of these APPGs fits TSW perfectly);

- Commission a Review of TSW similar in scope to the 'First Do No Harm' Review;
- Write to the British Association of Dermatologists to enquire if there is any current research into the adverse effects of prolonged steroid use and risks of withdrawal
- Modify the labels on topical steroid cream packaging to include prominent indications of their potency and clear warnings against overuse;
- Establish new evidence-based best practice around the prescription of topical steroids so that they are prescribed with correct and consistent usage instructions across all hospitals and GP practices
- Introduce a requirement for prescribers to regularly follow up patients prescribed topical steroids with awareness of the prospect of TSW in patients (and to make patients aware of the condition before they are prescribed them in the first place)

Please respond to my letter and outline the steps you intend to take to address the points above and keep me informed of any progress.

I look forward to hearing your response in due course.

Yours sincerely,
Rhianna Leigh

NB: For more information about Topical Steroid Withdrawal please visit:

<https://scratchthat.org.uk/>

<https://www.bbc.co.uk/news/uk-wales-56407982>

¹ <https://eczema.org/wp-content/uploads/Topical-Steroid-Withdrawal-position-statement.pdf>

² https://www.immdsreview.org.uk/downloads/IMMDSReview_Web.pdf

Letter template - <https://scratchthat.org.uk/mp-letter-guide/>
