

I thought it might be of interest to relate my own experience. In my early twenties [REDACTED]. I had my first outbreak of psoriasis. I used topical therapies for many years with limited results. By my early thirties I started getting psoriatic arthropathy as well. I did not seek systemic treatment at this stage as I knew that I would be prescribed methotrexate, and I did not wish to take this drug. As a result my disease gradually worsened, and by my mid-40s I had 30-40% of my body, including my face, covered with active plaques, as well as severe arthritic pain and a progressive limitation of movement.

Thankfully I did not seek treatment. Instead, in November 2012, I ordered a kilogram of [REDACTED] from a chemical supplier in [REDACTED]. I commenced self-medicating with [REDACTED] daily, and within a few months I estimate that I reduced my disease by at least 90%. Had I instead sought treatment through the public system I would have received inferior medications with the potential to cause serious harm. Had at least two of these treatments failed I would have waited for six months without effective treatment before being eligible for treatment with biologics. This could have made continuing full time employment very challenging.

I have gradually varied my drug dosage since commencement and documented my experience on a psoriasis website [REDACTED]. I currently have perhaps a couple of fingerprints of psoriasis, almost no arthritic pain, and joint damage which is slowly reversing. I have noted no loss of efficacy of the medication. My cost of medication is currently about 10 USD per year unsubsidised. Aside from my determination of what I believe to be a safer and more effective dosing regime, recent observations have alerted me to the likelihood that sun exposure can cause a lymphopaenia for patients taking [REDACTED]. The other implication for this observation is the possibility of combining [REDACTED] with radiotherapy to target inflammatory arthritis. I will assess my observation in coming months, but can only speculate within the timeframe for submissions.

The sad reality for me is that had I started with a deep contempt for the management of psoriasis and psoriatic arthropathy in Australia, I would have looked for treatments much earlier and probably avoided substantial damage. I believe my self-administered treatment to be better than any treatment I could receive in Australia. It is vastly superior on the objective measure of drug cost, and comparable with the best treatments on measures of efficacy, safety, customisation for disease severity and monitoring costs.

Under the current system of regulation there is no prospect of effective treatments for psoriasis like [REDACTED] gaining PBS approval, even when used in accordance with specialist guidelines. [REDACTED] is extremely cheap and is effective in up to 70% of patients with moderate to severe psoriasis. And let me be frank: The notion of a medical specialist prescribing [REDACTED] for psoriasis in Australia, given the absence of medico-legal support, has no likelihood of occurring. So for the TGA to suggest that this is possible to me is patronising, disingenuous and misleading. The wall of obfuscation I have experienced when seeking permission to import [REDACTED] will ensure that any further medication I require will have to be made in a backyard drug lab: You can imagine how this prospect colours my opinion. Surely it is time to regulate pharmaceuticals in this country via a sharing of authority between the TGA and specialist medical bodies under judicial oversight? The status quo advantages large pharmaceutical companies to the detriment of people with severe psoriasis and psoriatic arthropathy, and at the expense of taxpayers. In 2013, [REDACTED] received PBS approval for [REDACTED] to treat [REDACTED]. In 2015 [REDACTED] received over \$45 million from the Australian government for medication with a raw material cost of perhaps a few thousand dollars.

I conclude with some before and after images, The first set, taken some four weeks after commencing treatment, shows an extensive but healing disease and gives an indication of the joint damage. At the time I was very pleased with the degree of improvement. A current image set shows an almost complete clearance of psoriasis. I apologise for not taking an initial image. Hindsight is a wonderful thing.

Sincerely,

[REDACTED]