

## No.34 – Steroid Side Effects

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Title: **Steroid Side Effects**

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Sometimes it is necessary to point out the obvious. What is sometimes harder to understand is that what is obvious to us is not obvious to everyone. For example, it might be really obvious to you that the person you are eating with has a huge clump of parsley wedged in between his or her two front teeth, while they are completely oblivious to its presence.

To ITP patients that have taken steroid treatment, I am stating the obvious when I say that steroids are nasty. The side effects cover a broad spectrum, ranging from weight gain to eye troubles to mood swings. Scientifically, these side effects have been noted and recognized in study after study. However as a former ITP patient, I felt that the obvious problems with steroid treatment weren't so obvious to my physician.

Now, this is not to diminish my physician's work or expertise. In fact, it was my experience with that person that inspired me to pursue my own career as a physician. But just as our parsley pal needed someone to let him know he had a green glob marring his pearly whites, I felt someone needed to highlight the impact that steroid side effects were having on ITP patients.

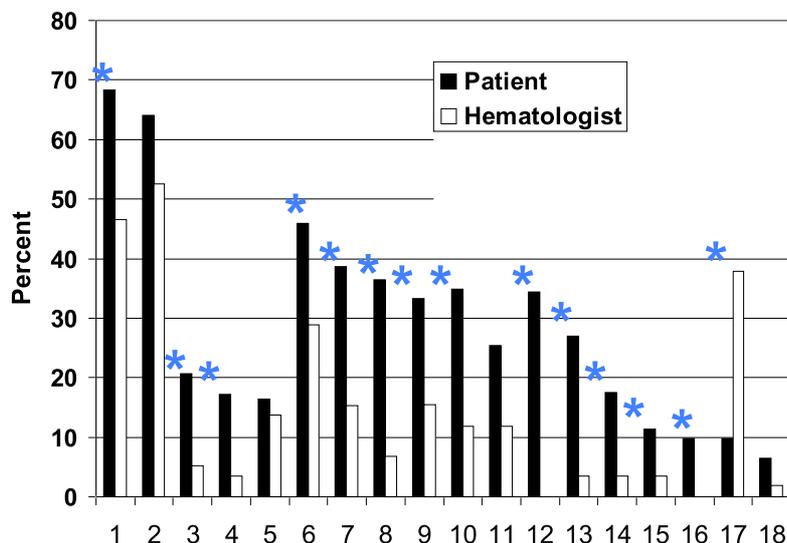
In order to document this, I developed a study about the difference in patient and hematologist perspectives about the side effects of steroid treatment and also the risk for bleeding in ITP. Under Dr. George's and Dr. Terrell's careful guidance, I developed two identical surveys, one for ITP patients and one for hematologists, and sent them to ITP patients and hematologists in the state of Oklahoma.

The survey specifically asked patients and hematologists about 38 different side effects related to steroid treatment, grouped into the 18 categories shown in Figure 1. Figure 1 represents the comparison of hematologists' responses (open bars) and patients' responses (black bars) about how frequently ITP patients experience severe (a lot of bother) corticosteroid side effects. The numbers in the Figure correspond to the numbers of each corticosteroid side effect listed below the Figure.

The difference between the patients' responses and the physicians' responses was statistically significant for 14 out of 18 categories, indicated by the stars. Of those 14 significant differences, 13 reported the patients experienced a lot more bother from that category of side effects than their hematologist recognized. (*See overleaf*)

The documented difference between the patients' and hematologists' perspectives should be an eye-opener to patients. Our physicians, even the most educated and compassionate, are not ITP patients themselves. Therefore, physicians need patients to communicate with them so that they know how much a side effect is bothering you. Just as physicians must educate patients about their illness, patients have a responsibility to educate their physicians about the actual problems they experience. We hope this study will be influential in the ways that ITP patients and physicians communicate and the way that steroids are prescribed for ITP patients in the future.

Recently, I got the splendid opportunity to travel to Europe for the first time to report the results of this study at your annual ITP Support Association Convention. At the Convention, we gave the same questionnaire in our study in Oklahoma to ITP patients in the United Kingdom. The results from the U.S. and U.K. surveys are compared overleaf.



**SIDE EFFECTS**

**Appearance**

- 1. Moon face, bloating, swelling
- 2. Weight gain/increased appetite
- 3. Hair loss
- 4. Acne
- 5. Stretch marks

**Emotional**

- 6. Insomnia, restlessness, and/or trouble sleeping
- 7. Anxiety and/or nervousness
- 8. Depression and/or stress
- 9. Anger and/or irritability

**Physical**

- 10. Generalized weakness, fatigue
- 11. Muscle weakness
- 12. Body pain (joint stiffness, muscle cramps, osteoporosis)
- 13. Hot flushes and/or sweating
- 14. Visual problems (light sensitivity/decreased visual acuity)
- 15. Nausea, upset stomach, vomiting, diarrhea

**Other**

- 16. Dizziness, headaches
- 17. Trouble with blood glucose levels, diabetes
- 18. High blood pressure

For both US and UK patients, the longest duration of prednisone was similar; at least one-third of the patients in each group had been on steroids for 12 months or longer. The largest part of the survey asked patients how bothered (“not at all bothered”, “a little bothered”, and “sometimes bothered” or “a lot bothered”) they were by 18 different side effects of steroid treatment. To compare the results of US and UK patients, we determined the number of different side effects for which patients reported that they were “a lot bothered”. Among the 30 participating UK patients at the Convention, the average patient reported they were “a lot bothered” by 4 of the 18 side effects. Among the 64 US patients surveyed in Oklahoma, the average patient reported that they were “a lot bothered” by 5 of the 18 side effects. For both groups, the range of how many side effects patients were “a lot bothered by” was from 0 to 12. There was no significant difference between these two results. This comparison was important because it documented that the problems with steroid side effects are the same for ITP patients in both the US and UK and suggests that they are probably the same for ITP patients everywhere. There were some differences between the US and UK patients, but we don’t know how important these are or the cause of the difference. US patients were more bothered by moon face, bloating, swelling, weight gain, and increased appetite. This may be because of America’s serious problems with obesity; just over 30 percent of Americans are obese and this may make some ITP patients more vulnerable to these particular steroid side effects. On the other hand, UK patients more often reported that they were “a lot bothered” with trouble sleeping.

The survey also contained a comparison of how worried patients were about bleeding risks at different platelet counts. Again, there was no difference between the UK and US patients in the amount of worry they reported experiencing about their risk for serious bleeding. Therefore, although we are on different continents, ITP, and especially its treatment with steroids, is affecting patients the same. These findings provide further evidence that current protocols for steroid treatment should be re-evaluated in an effort to match up physician and patient perspectives about the treatment of ITP.