



No. 12 – Alternative & Herbal

Two American Perspective articles reprinted from: **Sep 2002 & Mar 2003 (Reviewed and revised 2012)**

1. Alternative Treatments for ITP: A Survey of the Patients who Attended the ITP Support Association

Convention, April 2002

2. Are Herbal Remedies Safe?

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At the 2002 Convention in Huntingdon, we discussed the issues related to complementary and alternative treatments. We presented data demonstrating that in the US over half of people have used at least one alternative treatment. This is a huge business, with an estimated world-wide market for herbs/supplements/alternative medicines of \$46 billion. Drinks with herbal additives from manufacturers such as Pepsi-Cola and Cadbury Schwepps are the most rapidly growing segment of that industry. Last month I visited Sweden. My wife was buying some Indian spices in a small shop, things we can't find in Oklahoma, and I noticed a wall with over 200 small drawers containing different herbs and plant and flower extracts, recommended for every illness I know of, and many I don't. They seem harmless; many grow in our own gardens. It's easy to see why these alternative medicines are so accessible and attractive. However the problems are significant, because there are no guarantees about what is contained in these herbs and supplements, how effective they are, or what their risks may be. Despite these limitations, their use is growing. It has been suggested that individuals with serious illness are turning to these unproven treatments because there is less time in modern medicine for doctors to give personalized care to and show compassion for their patients. Certainly we all know that ITP can be a chronic and frustrating disorder. We have read many times in *The Platelet* about experiences patients have had with doctors who are neither expert nor comfortable in managing their problems with ITP. These are reasons why ITP patients may try alternative treatments.

At the April 2002 Convention, we asked patients to complete a questionnaire so we all could learn about their experience with alternative treatments. Mr. Ira Thomas, a student working with me, analyzed all of the information on the questionnaires. We inquired about how long they have had ITP, how it has been treated by their doctors, and what side effects occurred with these prescribed treatments. We also asked patients to report their use of alternative treatments. Then, in a separate questionnaire, we asked the five doctors who participated as lecturers at the Convention to estimate, among the patients they care for, how many patients they care for use alternative treatments. The data from the patients' questionnaires are presented in the accompanying Table. 48 patients completed the questionnaires, 30 (63%) have tried at least one alternative treatment (not counting the use of vitamin supplements). The range of the treatments that have been used is impressive – altogether 30 different alternative treatments have been used. Some patients have used as many as 11 different treatments. Older patients who have had ITP for a longer time and who have had a splenectomy may be more likely to have used an alternative treatment. These results are no surprise. This does not reflect that the patients are dissatisfied with their doctors; it only reflects frustration with a long, troublesome illness.

The estimates of the 5 doctors were quite different from what the patients reported. Again, there is no surprise here either. Very often doctors are not aware of their patients' use of alternative treatments. When the doctors' questionnaire results were combined, they estimated that only 15-20% of their patients may have tried an alternative treatment, compared to the 63% of patients who reported using an alternative treatment. Further, the doctors estimated that only 5% of their patients had ever discussed alternative treatments with them, in contrast to the patient reports, describing that 44% said they had talked with their doctors. These results emphasize among our own membership how widely alternative treatments are used, how great is their variety, and the difference between what patients are using and what physicians think they are using. We cannot say that alternative treatments are not helpful; some treatments may help some people. But we don't know that for sure. Also, we must always be careful about these treatments, because there is no knowledge about possible risks. We consider the major lessons from this survey to be that we as doctors need a better bond with our patients, improved understanding of their frustrations, and appreciation of the variety of treatments they are using. This is

what we are teaching our students.

TABLE: Use of alternative treatments reported by 48 patients attending the ITP Convention, April 2002.

- No alternative treatments used: 8 patients
- Vitamins only used: 10 patients
- Alternative treatments used: 30 patients

continued overleaf

Number of patients who have used each type of alternative treatment:

Echinacea 9	Osteopathy 3	Ginseng 1	Linseed oil 1
Acupuncture 7	Hypnosis 3	Shiatsu 1	Intravenous Vitamin B 1
Yoga 7	Chinese herbs 2	Relaxation tape 1	Selenium 1
St. John's wort 6	Massage aromatherapy 2	Lecithin 1	Spirulina 1
Reflexology 5	2	Chondroitin 1	Kelp 1
Commercial diet therapy 5	Star flower oil 2	Herbs 1	Calcium pathonate 1
Spiritual healing 4	Reiki 2	Bowen technique 1	
Homeopathy 4	Glucosamine 2	Evening primrose 1	
	Allium sativum 1		

[Ed: Please note – Echinacea is advertised as 'boosting' the immune system and thus should not be taken by anyone diagnosed with an autoimmune disease. In ITP patients the immune system is working extremely effectively (albeit misdirected) to destroy platelets, and does not require any boosting to increase this activity!]

IN THE September 2002 issue of *The Platelet*, we described our presentation to the 2002 ITP Convention about complementary and alternative medicines. This included a survey of ITP patients and their families who attended the April 2002 Convention indicating that 63% of them described having used 1–9 different forms of complementary/alternative medicine. This practice among our patients is similar to reports from America and Europe that many, if not most, patients with persistent, troublesome illnesses use complementary/alternative medicines at some point.

The use of complementary/alternative medicines continues to receive intense study. In the December 19, 2002 issue of *The New England Journal of Medicine*, one of the world's most influential medical journals, three articles devoted to herbal remedies emphasized that they are a serious and growing public health problem. In particular, these articles emphasize the lack of quality assurance for herbal remedies, that these remedies are not subjected to the same controls required for licensing of traditional medicines. Amounts of active ingredients may vary enormously between products. For example, a study of six different Ginseng preparations demonstrated that some products contained only 10% as much of the active ingredient as was stated on the label while others contained three times the amount that was stated on the label.

Moreover, herbal remedies have been found to contain active drugs that were not listed on the label (such as digitalis compounds), some have been contaminated by bacteria such as salmonella, others have contained pesticides, and many have contained toxic metals such as lead and mercury. One study screening more than 500 Chinese patent medicines found that 10% contained undeclared drugs or toxic metals. In US poison control centers, there were 19,468 reports of reactions to herbal medicines in 2001, up from 6914 in 1998. However the US Food and Drug Administration (FDA) is often unable to investigate these reports because the ingredients in the herbal remedy and the manufacturer are often not identified.

Products containing ephedra are commonly used to curb appetite and increase energy. Ephedra is similar to the drug methamphetamine, known among drug abusers as "speed". An estimated 12 million people in the US use a product named "Metabolife 356" that contains ephedra, caffeine, and several herbs. A recent investigation revealed that the manufacturer has received 13,000 complaints, including reports of deaths. All of these observations demonstrate the rising concerns about the safety of herbal remedies, related to the remarkable increase in their use. As a result of these concerns, the European Commission and the US FDA are considering new rules to review the safety of herbal remedies, regulations for advertising claims about health benefits, and authority to remove unsafe products from the market.

We and many others believe that manufacturers of herbal remedies should provide evidence of safe manufacturing practices and be required to report all adverse effects to the appropriate regulatory

agencies. Most importantly, the labels of these herbal remedies must contain a complete and accurate list of what they contain by both their botanical and common names. In the United States, the National Institute of Health has established a National Center for Complementary and Alternative Medicine to conduct scientific studies on the safety and effectiveness of herbal remedies. However, this research has been difficult because commercial sources of these herbs often lack careful production standards, and the content of the products is very different from batch to batch. These necessary studies should unequivocally document whether various herbal compounds are effective and safe.

No one, including the physicians, is happy with the side effects and inconsistent benefits of steroids, intravenous immunoglobulin, splenectomy, and other approaches used to treat ITP. But do remember this: each of these treatments has a firm scientific rationale for its benefits, and there is clear evidence that each of them can be highly beneficial in many persons with ITP. The same cannot be said for alternative and complementary medications, where there is no scientific evidence that they are useful. Just because a person with ITP 'feels better' after taking an herbal preparation is not scientific evidence. This 'better feeling' could also have happened by chance or could have occurred after eating a lump of sugar. Or it may be the result of the supportive manner of practitioners of complementary and alternative medicine, who often are better at spending time and providing optimism than busy medical doctors.

The most important lesson for readers of *The Platelet* is that just because an herb is natural does not mean that it is safe, and claims of remarkable healing powers are not supported by firm evidence. So beware of herbal remedies!

(This information was presented in these 3 articles:

Straus SE. Herbal medicines – what's in the bottle? *New Eng J Med* 2002;347:1997; De Smet PAGM.

Herbal remedies. *New Eng J Med* 2002; 347:2046; Marcus DM, Grollman AP.

Botanical medicines – the need for new regulations. *New Eng J Med* 2002:347; 2073.)