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**Titles: Alternative Treatments for ITP: A Survey of the Patients who Attended the ITP Support Association Convention, April 2002** Author: **James N. George, M.D., George R. Buchanan, M.D, Ira Thomas, M.D.**

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 to have 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

**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	Star flower oil 2	Chondroitin 1	Kelp 1
Commercial diet therapy 5	Reiki 2	Herbs 1	Calcium pathonate 1
Spiritual healing 4	Glucosamine 2	Bowen technique 1	
Homeopathy 4	Allium sativum 1	Evening primrose 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!]*