



No. 38 – Who cares for patients with

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Title: **Who Cares for Patients with ITP?**

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We want to describe our American experience for care of patients with ITP. Some of our experience is relevant everywhere; some may only be relevant for the U.S. because of our education and healthcare systems. What we describe is based on the assumption that patients have adequate insurance and optimal access for healthcare, which is currently not true for many people in the U.S.

Patient care for all diseases is based on three key elements: [1] Evidence for understanding the course of the disease and for the benefits and harms of treatments; [2] Doctor experience; [3] Patient preference. These three elements are all of equal importance. For ITP, evidence is limited. Although we have learned a lot from recent research, there are still many uncertainties about the long-term course of patients with ITP, what treatments to use and when to use them, and when it's best to use no treatment at all. This is different than the case for much more common disorders, such as heart attack and breast cancer, where substantial evidence allows the development of standardized methods of treatment. Therefore care for patients with ITP often depends on the next two key elements, doctor experience and patient preference. We emphasize that doctor experience alone is not sufficient for the best care; patient preference is equally important.

In the U.S., there are three levels of doctors who are involved in the care of patients with ITP. First are family doctors (comparable to the U.K. general practitioner) who see patients of all ages and manage problems of all kinds, including minor surgery and management of pregnancy and delivery. The next level of specialization is pediatricians and internal medicine doctors who focus on children or adults and only on medical, as opposed to surgical, problems. The third level of specialization is pediatricians and internal medicine doctors who take 2-3 years of additional training to become specialists. For patients with ITP, of course the relevant specialty is hematology. In the U.S., all hematologists are created equal (to paraphrase what one of our American founders, Thomas Jefferson, wrote 235 years ago). There are some exceptions, but across the U.S. most all hematologists see all blood related problems. In some University Centers, there may be distinctions between those who care for malignant disorders, such as leukemia and lymphoma, and others who care for benign disorders such as ITP. This difference represents the hematologists' interest and perhaps also a research focus.

Some hematologists may have more experience and knowledge about ITP and some have focused their careers on research related to ITP. But a career focus on ITP and research on ITP may not make that hematologist the best doctor for some patients. In some situations, the best hematologist for a patient with ITP may only see a few patients with ITP. This is not a problem; conscientious hematologists always ask others for advice when they need it. We believe that a more important criterion is that some hematologists may be more effective for talking with patients and listening to patients, to be able to better understand their questions and problems and to plan for the best care. When we are asked to suggest a hematologist for a patient, we chose the hematologist who we think is the best listener and who makes good decisions together with his or her patients, not necessarily the hematologist who sees the most patients with ITP. The doctor-patient relation is a little bit like a marriage – the couple has to be compatible. Some doctors like to control everything, and that's OK for some patients but not for all. Some doctors are better about listening to their patients, and that is crucial for some patients but not for all.

Although almost all patients with ITP in the U.S. are diagnosed and managed, for at least part of the time, by hematologists, much of their care is done by their primary care physician, either an internal medicine doctor, family medicine doctor, or pediatrician. We feel this is very effective because many problems that occur in patients with ITP are not just related to the ITP; patients with ITP also have all of the problems that all other people have. General medical care in collaboration with a hematologist is the best care, rather than only hematologist care. Therefore our experience is that the most effective care for patients with ITP is when all three people are involved in decisions: the patient, the patient's primary care doctor, and a hematologist.

Patients (or the parents of children) with ITP must be well-informed about its potential problems and with the benefits and risks of the different treatments, and they must actively participate in the decisions related to their care. For their part, doctors should assume that all decisions will be made jointly together with their patients. Patient participation in decision making is described as health literacy. There is clear evidence that health literacy affects health outcomes. For example a recent study of patients with heart failure documented that low health literacy was significantly associated with higher mortality. Health literacy is what The ITP Support Association is all about. There is no better resource for learning what you need to know about ITP than reading the materials that the ITP Support Association has prepared, reading *The Platelet*, and attending the annual Convention. There is really no excuse for low health literacy about ITP!

A clear example of the requirement for shared decisions between doctors and their patients is the experience of Jacqueline Guidry, our medical student who had been a patient with ITP when she was a teenager. She surveyed patients in the Oklahoma ITP Registry and all hematologists in the state of Oklahoma about the side effects of steroid treatment. Her surveys clearly demonstrated that patients had more problems with steroid side effects than their doctors appreciated; this emphasized the critical importance of improving communication between doctors and patients. Her surveys also documented that the doctors were more worried about risk for bleeding than their patients were. These different perspectives commonly led to overuse of steroids as doctors did not appreciate the patients' perspective and perhaps overestimated risk for bleeding. Jacqueline wrote about her research in previous *American Perspective* columns and presented her story to the ITP Support Association Convention in 2009.

So who provides the best care for patients with ITP? The answer is an interested doctor who listens to her patient together with a patient who understands the problems of ITP and discusses them with her doctor. Both are essential.