



No. 22 Fatigue in Patients with ITP

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Title: **Feelings of Fatigue in Patients with ITP**

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We've learned from our patients with ITP that many of them have symptoms of fatigue. When I've asked people attending the annual ITP Support Association Convention if they are bothered by fatigue, almost everyone raises their hand. Fatigue has been documented in focus groups of patients with ITP; in these groups, over 90% of patients have described symptoms of fatigue. Many patients say that their symptoms of fatigue are worse when their platelet count is low. But in spite of all of these experiences, doctors caring for patients with ITP commonly dismiss symptoms of fatigue as unimportant. This contrast, between what patients describe and what doctors believe, is an important problem for the care of ITP patients. It is a problem that the ITP Support Association is committed to solve.

There are several reasons why doctors do not believe that fatigue is an important problem for patients with ITP. First, doctors don't understand why fatigue may occur. ITP is a disorder apparently limited to blood platelets, and the only well known function of blood platelets is to prevent bleeding. Therefore bleeding and bruising symptoms are the only problems that doctors are concerned about as they care for ITP patients. Second, fatigue is something everyone has sometime. The doctor herself may feel fatigued as she listens to an ITP patient describing fatigue, and therefore she may think this is unrelated to ITP. Third, even if the doctor accepted that a patient's fatigue was a real problem that is really associated with the ITP, she may not know what to do about it. Finally, there have been no objective data to convince doctors that fatigue is actually a problem associated with ITP. There has been no study of a large number of ITP patients that used standardized and validated questions to determine the actual frequency of fatigue among ITP patients. Until now.

The ITP Support Association began its effort to correct this problem with the presentation of Dr. Julia Newton of Newcastle at the 2009 Convention in Edinburgh. Dr. Newton is a physician who specializes in understanding the causes and determining effective treatment of fatigue in many different diseases – but not ITP. She learned a lot about ITP at the Convention and she has become the leader of the Support Association's effort. With the help of Shirley Watson, Dr. Newton created a comprehensive survey to define fatigue in adult patients with ITP. One year ago, the Support Association distributed these surveys about fatigue to all 1871 of its members; 31% responded. We sent the same survey to the 93 patients enrolled in the Oklahoma ITP Registry; 74% responded. The survey contained specific and standardized questions about fatigue that have been used in previous studies of patients with multiple different diseases as well as healthy people. The results of the survey are remarkable. First, most patients reported significant fatigue, whether or not their ITP was currently active. (We defined patients as having "active ITP" if their platelet count was low and/or they were currently taking treatment for ITP.) The frequency of fatigue was greater in patients with active ITP than among patients whose ITP was in remission. 43% of the 386 patients who had active ITP had significant fatigue, determined by their responses to these questions; 28% of the 226 patients with ITP in remission also had significant fatigue. These are both greater than the expected 2.5% frequency of fatigue in healthy people. The presence of fatigue was not different between the UK and US patient groups. Other parts of the questionnaire asked about symptoms of dizziness (for example, feeling dizzy when you first stand up or remain standing for a long time) and symptoms of daytime sleepiness. These problems were related to the frequency of fatigue and may provide clues as to the cause of fatigue in patients with ITP and its possible treatment. Another important result of this survey was the things that were not related to fatigue. The presence of fatigue was not related to how old our patients are, whether they were men or women, how long they have had ITP, and whether or not they have had a splenectomy.

The most important conclusion is that the ITP Support Association's survey confirmed that fatigue is an important problem among patients with ITP. This may not be news for patients with ITP, but it is important news for their doctors. Based on these data, doctors may now believe that the symptoms of fatigue in patients with ITP are real, and they may now believe that fatigue is a real part of ITP. Based on Dr. Newton's experience with studies of fatigue in other diseases, there may be other tests that can help us to determine what may be causing the fatigue in ITP patients and how it may be treated. These studies by the ITP Support Association will help to improve the lives of our patients.