

ITP Patient Questionnaire Key Findings

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Although ITP is a rare disease, its impact on a patient's life may be significant. In a recent questionnaire conducted among members of the Platelet Disorder Support Association, respondents said that having ITP interferes with their regular activities, affecting their daily lifestyle. However, a majority of respondents said that they feel optimistic that their ITP can be managed, and most respondents said an oral ITP medicine would have a positive impact on their quality of life.

- More than half of respondents said they felt bothered by “anxiety or fear” over what ITP means in terms of their daily lifestyle activities. Respondents said **ITP has moderately, strongly or completely interfered with their regular activities**, as follows:
 - 60 percent said exercising/sports
 - 54 percent said their mood
 - 44 percent said travel
 - 36 percent said job responsibilities
 - 35 percent said household chores
 - 34 percent said social activities
 - 31 percent said taking care of a child or other family member
 - 27 percent said maintaining relationships with friends/family
 - 19 percent said hobbies
- Among the respondents who work, **30 percent said they feel that co-workers have treated them differently** since being diagnosed with ITP. **Thirty-five percent said that they felt the need to hide their diagnosis** from co-workers.
- Most respondents said they felt that an oral ITP medicine would have a positive impact on their quality of life.
 - 85 percent of respondents said having an oral ITP medicine would have a positive impact on **flexibility and/or freedom in their lifestyle**
 - 71 percent said having an oral ITP medicine would have a positive impact on **improving their attitude towards their overall health and ITP diagnosis**
 - 82 percent said having an oral ITP medicine would have a positive impact on their **ability to take their medication when they should and in the right amount**
- Eighty-eight percent of respondents said they felt that **a treatment that does not interfere with their daily lifestyle is important**. ITP patients also said the following are important for their treatments:
 - 97 percent said having a **safe treatment**
 - 95 percent said **a treatment with very few side effects**
 - **93 percent said a treatment that keeps platelet counts at a healthy level**
 - 76 percent said a treatment that **is convenient**
- When asked the degree to which they experience various signs, symptoms and concerns associated with their ITP disorder, respondents found the **following symptoms of ITP to be bothersome**:
 - 67 percent said being tired when doing daily activities
 - 63 percent said bruising when they bump into things
 - 57 percent said anxiety/fear over what ITP means in daily life
 - 29 percent said gums bleeding when brushing teeth
- Most respondents (90 percent) said they **go to the Platelet Disorder Support Association** and www.pdsa.org for more information about ITP. Additional sources for information include:
 - 81 percent said doctor
 - 27 percent said other patients with ITP
 - 18 percent said www.lowplatelets.com
 - 10 percent said family
 - 10 percent said local support groups
- When asked how they currently feel about their ITP diagnosis, a majority (56 percent) of respondents said they **currently feel optimistic that their ITP can be managed** and 50 percent said they are **hopeful for new treatments**. Forty-one percent said they are **glad they understand their diagnosis**.
 - However, 44 percent are worried about the future, 31 percent are discouraged about treatment options currently available and 7 percent are confused about what their diagnosis means.

Methodology: The results are based on a questionnaire conducted among 251 members of the Platelet Disorder Support Association with acute or chronic immune (idiopathic) thrombocytopenic purpura (ITP). The questionnaire was conducted online from August 17, 2009 through September 22, 2009 and included 178 women and 73 men with acute or chronic ITP. From an opt-in e-mail distribution to 859 PDSA contacts, the margin of error for a sample of 251 is approximately +/- 5.21 percent.

The findings of this questionnaire are not statistically significant.

The information presented here may not be representative of all ITP patients or individual experiences.