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Novartis survey uncovers real-world impact of immune thrombocytopenia

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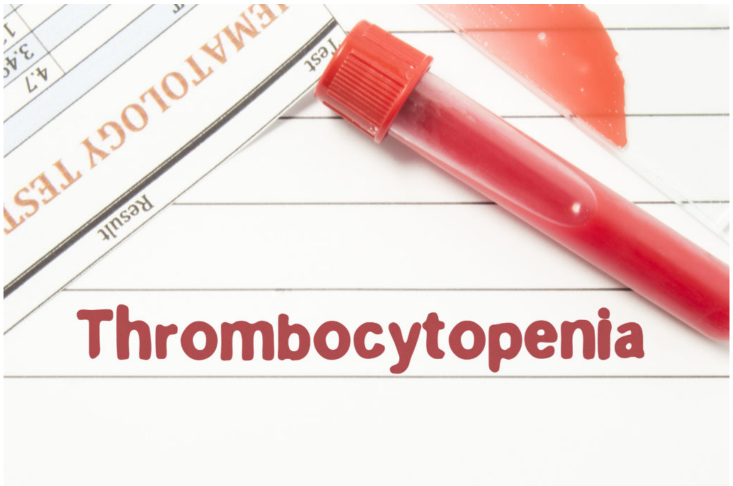
Findings from more than 1,300 patients across 13 countries showed ITP had especially high impact for many patients on emotional well-being (36%) and ability to work (28%)



Many patients with the rare blood disorder immune thrombocytopenia (ITP) find the disease has a negative impact on their everyday quality of life, according to interim results of a Novartis survey, called I-WISh, presented today at the 23rd Congress of the European Hematology Association (EHA) in Stockholm, Sweden (Abstract #PF654).

I-WISh, collaboration among global ITP experts, patient groups and Novartis, aims to uncover the impact of the disease on daily life, and patients' perceptions toward treatment and management of their condition.

Interim survey results from more than 1,300 ITP patients revealed that they have concerns about the impact of ITP on their quality of life. Results showed that more than one-third (36%) of patients said that having ITP had a high impact on their emotional well-being while 28% of patients had disease symptoms that caused them to miss work. About two-thirds of patients reported that fatigue was their most severe symptom at diagnosis (71%) and at survey completion (64%).

"Severe fatigue, in particular, was reported by many patients as the most difficult to manage symptom of ITP," said Nichola Cooper, MD, clinical senior lecturer, Hammersmith Hospital, Imperial College London,United Kingdom, and Chair of the I-WISh Steering Committee. "This is an important message for healthcare providers treating patients with this rare disease; ITP is about more than bruising and risk of bleeding."

The I-WISh Steering Committee developed the ITP Life Quality Index (ILQI), a ten-question tool designed to help quantify and monitor the quality of life impact of ITP on patients. The ILQI was validated in qualitative analyses prior to being unveiled in the I-WISh survey and will allow clinicians to better monitor symptoms beyond bleeding and to rely on more than platelet counts when treating ITP patients.

Overall, the two main treatment goals reported by patients were achieving healthy blood counts (79%) and increasing their energy levels (55%).

"These initial data from the I-WISh survey reveal how a rare blood disease like ITP can significantly affect a patient's ability to live and function in their day-to-day life," said Samit Hirawat, MD, Head, Novartis Oncology Global Drug Development. "We believe these results demonstrate that, even beyond medicine, ITP patients are seeking compassion, support and understanding from family, friends so they can strive to live the best lives they can. These are important insights, and we will look to build them into the programs and services we develop to better support this community."

To raise awareness about ITP, Novartis has launched the #ITP3Wishes social media campaign to give voice to the hopes and dreams of patients and those who support them. The campaign encourages people to use their social media channels to share three ITP-related wishes with the #ITP3Wishes hashtag to inspire others and let their ITP voice be heard.