

Novartis survey uncovers real-world impact of immune thrombocytopenia or ITP, a rare blood disease, on patients' quality of life

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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%)
- -- About two-thirds of patients reported fatigue as the most severe symptom at diagnosis and survey completion, underscoring the effect of ITP on day-to-day quality of life
- -- Interim results of the ITP World Impact Survey (I-WISH) one of the largest surveys ever conducted in ITP, were presented at EHA

EAST HANOVER, N.J., June 15, 2018 /PRNewswire/ -- 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, a 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, 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 patients¹.

"Some patients only realize their fatigue has become such an issue in their daily lives after it is corrected by treatment," said Dr. Cooper. "The ILQI tool will help measure this correction more accurately and could also play a crucial role in monitoring disease impact on quality of life beyond just relying on the platelet count alone."

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.

About the ITP World Impact Survey (I-WISh)

The international I-WISh survey is a cross-sectional survey of 1,400 patients with ITP and 480 healthcare providers who treat the condition from 14 countries (Canada, China, Colombia, Egypt, France, Germany, Italy, India, Japan, Norway, Spain, Turkey, United Kingdom and United States). The interim results were from more than 1,300 patients in 13 countries who completed an online questionnaire beginning in January 2018 to measure ITP-related symptoms and the impact of the condition on daily life, and patients' perceptions toward treatment and management of their condition. Additional survey results will be presented later this year.

About the ITP Life Quality Index (ILQI)¹

The ITP Life Quality Index (ILQI) was originally developed by clinical experts and based on patient interviews that were conducted to provide evidence to confirm content validity, specifically regarding the relevance of concepts. A literature search was performed prior to the interviews to ensure the ILQI captured relevant concepts.

Fifteen semi-structured patient interviews were conducted with UK patients with ITP recruited via the UK ITP Support Association. Patients were asked open-ended questions to elicit spontaneous discussion of their experience, followed by questions that probed the concepts of interest. The interviews also involved cognitive debriefing of the ILQI using 'think-aloud' methods to assess understanding and relevance of items, instructions and response options. Verbatim transcripts were analyzed using thematic analysis techniques.

Patients were 67% female, had a mean age of 51.3 (SD=17.4, range 23-73) and a range of education levels. Qualitative analysis identified a variety of impacts associated with ITP, including fatigue (93%), emotional impacts (e.g., anxiety [80%]), impacts on daily living such as lack of ability to partake in sport (100%), impacts on work (e.g., absenteeism [40%]), financial impacts (e.g., working hours [40%]) and social impacts (e.g., relationship with family [60%]).

About Immune Thrombocytopenia (ITP)

Immune thrombocytopenia (ITP) is a rare and potentially serious blood disorder that is characterized by increased destruction and impaired production of platelets, which are blood cells that allow the blood to clot properly². People who have ITP often have purple bruises or tiny red or purple dots on the skin³. They also display symptoms such as nosebleeds, bleeding from the gums during dental work, or other bleeding that is hard to stop². The potential for drops in platelet counts may also cause emotional distress and may result in a hindered ability to do work or embarrassment due to visible symptoms³.

Immune thrombocytopenia is classified by duration from diagnosis into: newly diagnosed (0-3 months), persistent (3-12 months duration) and chronic (>12 months duration). Chronic ITP is more likely to occur in adults, and women are affected more often than men².

The goal of treatment in ITP is to maintain a safe platelet count that reduces the risk of bleeding. Treatment is determined by platelet levels and the severity of the symptoms. In most cases, drugs that alter the immune system's attack on the platelets are prescribed to help manage bleeding in adults.

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