**New European Survey of ITP: Insight into Treatment Experience for Patients with Rare Blood Disorder**

A recent survey conducted by an international market research company; Kantar Health, sought insight into the experience of patients suffering from a highly debilitating and rare blood disorder called immune thrombocytopenia (ITP) characterised by low platelet counts in the blood (thrombocytopenia), which can lead to severe bleeding events. The survey, which was sponsored by Amgen (Europe) GmbH, was developed to better understand the impact and experience of ITP on patients in Europe.

***Key Survey Findings***

**Highlights**

- Impact on patients' daily lives is severe
- Most patients would like to have more advice from healthcare professionals
- 60% of patients were being or had been prescribed steroids
- 40% of patients had received at least three or more different therapies over time
- 80% of patients feel that their treatment could be improved by at least one factor
- Most important factors for treatment are proven safety record and effectiveness at maintaining target platelet count over time
- Patients keen to learn about new therapies and use internet for information

- ***Impact of ITP*** - Although ITP is a rare disease, patients reported that they feel the impact of the condition on their daily lives is severe, causing them anxiety and concern.

- ***Support Systems*** - Most patients questioned stated that they were satisfied with the support they had received from physicians, adding that diagnosis was quick, often within three months. They also felt that they received enough information about their condition and were given strong emotional support.

  Furthermore, although patients reported that they were satisfied with the support that they had received from physicians, two-thirds of respondents stated they would like to have more healthcare professional advice and expert information than they are currently receiving, to help them better manage their condition.

- ***Patient Treatment Experience*** - When questioned about their treatment path, sixty percent of patients reported that they were being or had been prescribed steroids. A further forty percent of patients had received at least three or more different therapies over time, suggesting that patients are not being managed on one therapy alone.

  Eighty percent of patients reported that they felt that their treatment could be improved by at least one factor; citing efficacy, fewer side effects and less frequent administration as the main areas. They also believed that one of the most important factors about a treatment is if it has a proven safety record and is effective at maintaining target platelet count over time.

- ***Access to ITP Information*** – According to the survey, when patients asked their physicians about treatment options, older therapies such as steroids and splenectomy were most commonly discussed. When patients actively sought more information about ITP from other

sources, they were most keen to learn about treatment options and specifically newer therapies.

In terms of where patients found their information, patients reported that more than half of the information came from the internet, suggesting that ITP patients are keen to search online and there are opportunities to support them further through this medium.

- **About ITP**

  Adult chronic ITP affects an estimated 2.0 per 100,000 patients in the European Union (EU)[1,2] and is a rare and serious autoimmune disorder, which occurs when immune system cells (specialised lymphocytes) produce antibodies that cause the destruction of platelets in the spleen and other organs. The specific cause of ITP is unknown and in most adults it is a chronic condition.

- ***Survey Background***

  The ITP Patient Experience survey took place across six European countries; *UK, Italy, Germany, France, Spain* and *The Netherlands*. It collected data from a sample of 158 patients across Europe using a mix of face- to- face, telephone and online methodologies to interview respondents.

  The majority of the patients interviewed (69%) were first diagnosed at least *4 years ago*. The patients had a mean platelet count of 67, 961 per millilitres with a mean age of 47.8 years old. Nearly three quarters (72%) of the respondents were female.

**References**

[1] McMillan R. Therapy for Adults with Refractory Chronic Immune Thrombocytopenic Purpura. *Ann Intern Med* 1997;126:307-314
[2] Fogarty PF et al. *Curr Opin Hematol* 2007;14:515-519