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IPOPI announces publication of global study on PID Patients Needs and Outlooks

Cornwall, UK 5th May 2014 – The International Patient Organisation for Primary Immunodeficiencies' (IPOPI) today announced the published results of the first global study of its kind demonstrating the importance of providing access to different treatment options and modes of administration to ensure individual patient needs are best met. The study, "Improving current immunoglobulin therapy for patients with primary immunodeficiency: quality of life and treatment views¹" was published in the 2 May, 2014 edition of the journal *Patient Preference and Adherence*.

"One of the objectives of IPOPI is to stimulate global efforts to improve awareness, diagnosis, treatment and quality of life of people with primary immunodeficiencies (PID)," said Jose Drabwell, Chair of IPOPI Board. "The survey highlights the importance of providing access to different treatment options and routes of administration to ensure individual patient needs are best met. Patient and physician choice of treatment is a key priority for our patients' community"

The survey's main results found that most respondents (76%) were satisfied with current treatment, reflecting the benefits that Ig therapy provides to patient health and well-being. However, patients remained below physical and mental well-being norms for HRQoL determined by the questionnaire. All respondents expressed the desire for a 4-weekly infusion, the ability to administer at home, self-administration, shorter administration duration, and fewer needle sticks.

"IPOPI's global survey provides a clear confirmation that immunoglobulin replacement therapy enables PID patients to lead active and productive lives and improves quality of life



significantly,” said Dr. Teresa Espanol, Immunology Unit, Vall d’Hebron University Hospital, Barcelona, Spain. “Sixty-six percent of intravenous immunoglobulin replacement therapy (IVIg) respondents and 69% of subcutaneous immunoglobulin (SCIg) respondents reported missing 10 or fewer work/school days due to ill health during the past 6 months. 35% of IVIg respondents and 37% of SCIg respondents reported 0 absences, a clear improvement compared to their health status before IG therapy was commenced.”

An online questionnaire was made available through IPOPI to patients with PID and their caregivers from April 2011 to October 2011 regarding patients’ current treatment, satisfaction, living with PID and patient preferences using a conjoint approach (a research technique for eliciting and quantifying preferences). Health-related quality of life (HRQoL) was collected via questionnaires using the SF12 Health Survey and EQ-5D (the validated QoL scale).

The study was funded by Baxter Healthcare SA.

About IPOPI

www.ipopi.org

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ⁱ Espanol T, et al. Improving current immunoglobulin therapy for patients with primary immunodeficiency: quality of life and treatment views. *Patient Preference and Adherence*. 2014;8 621-629.