

## Questionnaire for patients with Primary Immunodeficiency (PID) receiving immunoglobulin replacement therapy

### **12 Simple questions to help you and your healthcare professional (HCP) choose your best treatment option**

- ❖ Immunoglobulin replacement treatment is a life-long therapy and it is important for your HCP to know more about your lifestyle and preferences so he/she can choose the best option for you.
- ❖ Please take a few moments to answer the following questions. Your answers will help you and your HCP determine the appropriate option.

**Patient's name:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Surname:** \_\_\_\_\_

**Age:** \_\_\_\_\_

**1 ❖ If you have received immunoglobulin therapy in the past, what route of administration did you use? Mark all that apply.**

- ☐ Intravenous
- ☐ Subcutaneous
- ☐ Intramuscular
- ☐ I have not received immunoglobulin therapy in the past

**2 ❖ If you have received immunoglobulin therapy in the past, did you experience any complications with the chosen route of administration? Please write them below and score the level of severity from 1 to 5 (1-low; 5-high). Mark all that apply.**

- ☐ Intravenous: \_\_\_\_\_
- ☐ Subcutaneous: \_\_\_\_\_
- ☐ Intramuscular: \_\_\_\_\_
- ☐ I did not experience any side effect

**3 ❖ If you have received immunoglobulin therapy in the past, who administered the therapy to you? Mark all that apply.**

- ☐ Administered by a HCP
- ☐ Typically administered by a HCP, but sometimes self-administered (after I received a training)
- ☐ Typically self-administration, but sometimes administered by a HCP, e.g., prior to a vacation period
- ☐ Self-administration or administered by a family member/friend

**4 ❖ Who would you prefer to administer the immunoglobulin replacement therapy to you?**

- ☐ I prefer to administer my own therapy
- ☐ I prefer to have a partner, family member or friend to administer my therapy
- ☐ I prefer to have a HCP to administer my therapy

**5 ❖ Where would you like to receive your immunoglobulin treatment?**

- ☐ Medical setting (doctor's office, hospital, or infusion center)
- ☐ At home
- ☐ I do not have any preference

**6 ❖ Which kind of schedule would you prefer for receiving your infusions?**

- ☐ I prefer to have regularly scheduled visits
- ☐ I prefer to be personally responsible for maintaining my immunoglobulin administration schedule without nursing intervention
- ☐ I do not have a preference

**Medical center:** \_\_\_\_\_

**Doctor:** \_\_\_\_\_

**7✧ The total amount of time per month that it takes to administer your treatment can vary based on the Ig therapy that you choose. How would you prefer to receive your therapy?**

- ☐ One 3-hour infusion once every 3-4 weeks
- ☐ One to three infusions per week totaling approximately 2-8 hours per month
- ☐ I do not have a preference

**8✧ How do you feel towards the use of needles for your treatment? Circle yes or no for each line below.**

- ☐ I am comfortable for a HCP to administer my therapy with a needle – Yes or No
- ☐ I am comfortable using a needle to inject myself – Yes or No
- ☐ My caregiver is comfortable using a needle to administer my therapy – Yes or No

**9✧ Which of the following scenarios is representative of your lifestyle? Mark all that apply.**

- ☐ I work/study in a full-time schedule without flexibility
- ☐ I work/study in a full-time schedule with flexibility
- ☐ I work/study in a part-time schedule
- ☐ I tend to travel a lot
- ☐ I am retired
- ☐ I tend to have many scheduled activities during the week

**10✧ If you are considering self-administering your immunoglobulin therapy, are you comfortable storing and preparing your immunoglobulin therapy in the necessary sterile conditions at home?**

- ☐ Yes
- ☐ No

**11✧ How much social interaction do you prefer during your treatment?**

- ☐ I enjoy interacting with other patients and/or HCPs during my treatment
- ☐ Sometimes I like to interact, sometimes I like to be by myself. I do like to have the option to interact with other patients and/or HCPs if I feel like it
- ☐ I do not enjoy interacting with other patients and/or HCPs during my treatment

**12✧ What type of side effects would concern you the most? Choose among some of the most frequent ones and score the level of severity from 1 to 5 (1-low; 5-high):**

- ☐ Fatigue:
- ☐ Lumps at the injection site:
- ☐ Headache:
- ☐ Itching:
- ☐ Pain at the injection site:



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