

## Bill of Rights for Patients with Primary Immunodeficiency Disease

### Medical Information

- You have the right to be fully informed about your diagnosis, the treatment options for your disease and the prognosis, in terms that you can understand.

### Choice of Healthcare Provider

- You have the right to choose medical personnel who can deliver quality healthcare for your disease state.
- You have the right to request second opinions or consultations if you so choose without consequence.

### Involvement in Healthcare Decisions

- You have the right to be fully informed regarding what is involved with your treatment options, procedures, and potential complications, in a way that you can understand.
- You have the right to participate fully in any decisions regarding your treatment and/or procedures.
- You have the right to be informed of specific drug information such as IVIg/SCIG brand, dose, lot number, rate of infusion, expiration date as well as any special properties about each medication.
- You have the right to partner with your healthcare provider to address specific immunoglobulin product issues and individualize your treatment plan.
- You have the right to engage in conversation with your healthcare provider regarding options for therapies and services, regardless of health insurance policies.
- You have the right to the site of care and mode of treatment delivery that suits your needs.
- You have the right to refuse any drug, treatment or procedure.

### Fair Treatment and Non-discrimination

- You have the right to be respectfully treated and cared for from your doctors, health plan and any other healthcare providers regardless of race, sex, nationality, religion, sexual preference, or ability/source of payment.
- You have the right to be given the option of the Family and Medical Leave Act, based on the size of your employer, to address chronic absence from work due to a clinical condition.
- Children in school are entitled to protection of their rights under Section 504 of the Rehabilitation Act 1973.
- You have the right to request to have an insurance case manager assigned to your medical case.

### Privacy and Protection

- You have the right to speak privately with your healthcare providers.
- You have the right to confidentiality about your healthcare information.
- You have the right to know what is in your medical record and have a copy of your own medical record.
- You have the right to ask your doctor to change your record if it is not correct, relevant or complete.

### Grievances

- You have the right to petition and request review of any complaint you have against your health plan, doctor, hospital or other healthcare personnel.

*Created by the Immune Deficiency Foundation Nurse Advisory Committee in 2009, Revised in 2012*