

Bill of Rights for Individuals with Primary Immunodeficiency Diseases*

Medical Information

- You have the right to be fully informed about your diagnosis, all 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 participate fully in any decisions regarding your treatment and/or procedures.
- You have the right to be informed of your treatment, including specific drug information such as route of administration, brand, dose, lot number, rate of infusion (if applicable), expiration date as well as any special properties about each medication.
- 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 treatment options that are safe and effective for your specific form of PI, whether it be immunoglobulin therapy, hematopoietic stem cell transplantation, gene therapy, enzyme replacement therapy, interferon gamma, antibiotics and antifungals, etc.
- You have the right to refuse any drug, treatment, or procedure without retribution.
- You have the right to participate in or investigate clinical trials for your illness.

Fair Treatment and Non-discrimination

- You have the right to be respectfully treated and cared for from your healthcare provider, health plan and any other healthcare providers regardless of age, race, gender, nationality, religion, or sexual preference.
- 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.
- You have the right to request to have an insurance case manager assigned to your medical case.

Privacy and Protection

- You have specific legal privacy rights under HIPAA that may be found at U.S. Department of Health and Human Services: www.hhs.gov/hipaa.

Grievances

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

Created by the Immune Deficiency Foundation Nurse Advisory Committee in 2009. Revised in 2012, 2018, 2019.

**If you are a parent/caregiver of a child, under the age of 18, it is your responsibility to advocate for your child to receive these rights.*