Summary

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The studies reviewed and issues addressed in this supplement underscore the challenges facing patients with primary immunodeficiency disease (PI) and the physicians who treat them. The first article emphasizes the importance of individualized treatment driven by clinical outcomes for patients with PI and the fact that immunoglobulin G (IgG) products cannot be considered as generic. Different patients with PI may require very different dosing regimens to achieve protection against infections. Treatment based on trough IgG levels rather than clinical outcomes is contrary to current guidelines. Differences among products in IgA, sugar and sodium content, and osmolarity may have little or no effect on efficacy, but they may impact safety and tolerability in particular patient subsets. Problems faced by physicians and patients reviewed in the second article strongly support the belief that decisions made by insurers often ignore the clinical evidence that provides the basis for the use of intravenous or subcutaneous IgG. The failure of insurers to follow clinical guidance for the treatment of PI patients has resulted in problems with care that include delayed infusions, denial of reimbursements, cancelled treatment, changes in infusion site, switching to a less preferred or less well-tolerated product, and reduced dosages.

Barriers to appropriate care for PI raised by insurers require increased advocacy for patients at both the local and national levels. The case studies reviewed in the third article demonstrate that these interventions can be highly successful but require coordinated action from physicians and appropriate advocacy groups. These cases also make clear that negotiations with the insurer alone may not be effective and that actions aimed at healthcare regulators—and even the general public—may be necessary to achieve goals. Physicians and patients can take advantage of the lessons learned from these efforts and tools provided by the Immune Deficiency Foundation; the American Academy of Allergy, Asthma & Immunology; the Clinical Immunology Society; and other organizations to help ensure evidence-based initiation and continuation of IgG administration. Healthcare professionals involved in the care of individuals with PI must be aware of policies that may limit care for their patients, cooperate to combat negative and potentially dangerous policies, work to achieve better local and national regulation and legislation governing PI patient care, and increase their involvement with local and national organizations working to support these patients.

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