Imagine that you are a patient. Imagine that you have an impaired immune system that can cause you to get very, very sick...Maybe even kill you.

Imagine that the only thing between you and your hope to stay alive is a treatment that you aren’t getting because your access to the medication depends on reimbursement that is not there for you.

There are an estimated 250,000 patients in the United States who suffer from primary immune deficiency disease (PIDD). The majority of these patients require antibody replacement therapy, and they don’t have to imagine, because for them, this is exactly what is happening.

The only viable treatment for these patients is to receive a treatment that replaces missing parts of their immune systems through infusions called IVIG (intravenous immunoglobulin). Without it, these PIDD patients are highly susceptible to severe infections and debilitating illnesses and are at a significantly increased risk of death.

The significance of IVIG to patients with PIDD cannot be overstated.

There are no alternative treatments.

Beginning in early 2005, reports surfaced that patient access for Medicare beneficiaries was being compromised through the new payment system (ASP+6%) that went into effect on January 1st of that year. Congress took action. In August of 2005, the Ways & Means Subcommittee on Health and the Energy & Commerce Subcommittee on Health asked the Office of the Inspector General (OIG) to investigate.

Throughout late 2005 and early 2006, the OIG spoke with manufacturers, wholesalers and physicians affiliated with IVIG. The OIG then did surveys and collected data on supply and pricing. After nearly two years of investigation, the OIG sent preliminary updates to Congress, but has still not produced a final report with recommendations for dealing with the Medicare reimbursement problem.

The Secretary of HHS also asked for another study on the demand and supply of IVIG and that report has not been issued either.

Congress has said that it cannot act on a solution until it has seen final results and recommendations from these two studies. In the meantime, the Immune Deficiency Foundation (IDF) has conducted its own surveys which show that large numbers of Medicare patients are no longer being treated in their doctors’ offices because of inadequate reimbursement and are postponing treatments and increasing the intervals between treatments. The result for them is more infections, pneumonia, bronchitis, and increased use of antibiotics, among others.

The time has come for Congress to act. Pass legislation to deal with the reimbursement issues that have created access problems for patients who need IVIG.

We aren’t looking for special treatment; we’re just looking for treatment.

Patients can’t afford to wait anymore. It’s time to do the right thing—now—and assure that Medicare patients have access to IVIG they need to stay well and alive.