

The Salt Lake Tribune

Utah Medicare patients denied life-saving treatment

By Harry Hill

November 24, 2007

As the head of the section for clinical immunology/ immunodeficiency diseases at the University of Utah, I treat patients with primary (or genetically determined) immune deficiency diseases. Recently, an unintended consequence of federal Medicare legislation has had a very disturbing effect on PIDD patients and the health-care professionals who treat them.

PIDD is characterized by a weakened or absent immune system. As a result, the patients are extremely vulnerable to infection. For a patient with PIDD, a respiratory infection, for instance, could lead to pneumonia and an emergency room visit and possible hospitalization.

Many patients rely on a treatment called intravenous immune globulin. Without regular infusions of IVIG, these patients face the risk of serious, overwhelming infection and even death.

In 2005, there was a change in Medicare reimbursement for IVIG. It created a treatment access problem for patients by changing the way Medicare pays for IVIG therapy. This same legislation changed the policy for home health-care coverage as well, leaving many of these patients unable to afford treatment in their homes - the safest and least contaminated environment for patients with compromised immune systems.

Almost two years subsequent to this well-intentioned legislation, the IVIG access and reimbursement problem persists. Though I have eventually been able to help most of my patients find IVIG treatment, too often the patients struggle with serious infections and debilitating illnesses as a result of missing their regular treatments.

Gaps in treatment are not only dangerous to the health of these patients, but also result in severe emotional distress in many instances. IVIG is crucial to my patients, providing them with their only chance at living a normal and productive life. Needless to say, they often become distraught when they learn that Medicare's inadequate reimbursement policies limit their access to this life-saving treatment.

It is my understanding that patients and physicians nationwide are facing these same challenges. In April 2007, the Office of the Inspector General surveyed physicians regarding IVIG treatment procedures. More than 40 percent of physicians surveyed said Medicare payments are not enough to cover the actual cost of purchasing IVIG for their patients.

Because of this, many physicians, I am told, have been forced to discontinue IVIG infusions to Medicare beneficiaries altogether.

A recent patient survey sponsored by the Immune Deficiency Foundation reported many patients had to postpone and/or reduce frequency of treatment because of these reimbursement problems. As a result, they are at a higher risk of hospitalization with serious infections, which, ironically, almost always becomes more costly to Medicare.

But there is hope. A bill called the Medicare IVIG Access Act, recently introduced in Congress, provides a solution to this crisis by establishing a process for reviewing IVIG reimbursement and adjusting rates appropriately. The bill, HR2914, also authorizes Medicare to pay for the costs of administering IVIG in the home, giving patients a safer, more convenient option for treatment location, which is also less expensive and probably even safer.

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Similar legislation has not yet been introduced in the Senate, but it's important that senators be made aware of the issue before they act on Medicare measures this fall. I ask, on behalf of the patients, families and physicians in our community, that Utah's Sen. Orrin Hatch and Sen. Bob Bennett take a leadership role in ensuring that there is proper access to treatment and medication for patients with primary immune-deficiency diseases.

These patients can't afford to wait. They need your help now.

* HARRY HILL is a professor of pathology, pediatrics and medicine at the University of Utah.