Improving Lives • Finding the Cure

August 14, 2012

Re: Comments on the Essential Health Benefit Mandates and Benchmark Plans prepared for New York.

On behalf of the International Myeloma Foundation (IMF), the oldest and largest myeloma foundation dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure, we are writing to submit comments on the Essential Health Benefit Mandates and Benchmark Plans that you are considering.

Background about Myeloma and its Treatments

The second most common blood cancer worldwide, multiple myeloma (or myeloma) is a cancer of plasma cells in the bone marrow. It is called "multiple" because the cancer can occur at multiple sites in multiple bones. Each year approximately 20,000 Americans are diagnosed with myeloma and 10,000 lose their battle with this disease. Once a disease of the elderly, it is now being found in increasing numbers in people under 65. At any one time there are over 100,000 myeloma patients undergoing treatment for their disease in the U.S. Although the incidence of many cancers is decreasing, the number of myeloma cases is on the rise. There is no cure for myeloma, remissions are not always permanent, and additional treatment options are essential. Fortunately, we have seen dramatic and important advances in treatments for multiple myeloma.

Treatments for myeloma include four targeted /anticancer therapies, two injectables and two orally administered drugs, as well as stem cell transplants. (The term "targeted therapy" refers to a type of medication that blocks the growth of cancer cells by interfering with specific targeted molecules needed for the creation of cancer, or, carcinogenesis, and tumor growth.) Targeted therapies can be given to cure cancer, control it, or ease cancer symptoms.

In the past, traditional cancer treatment, or, chemotherapy, was primarily delivered by IV or injection, but orally administered drugs have become the standard of care for many cancer types, including myeloma.

Myeloma is a recurring disease, so patients typically cycle through all of the treatment options as they attempt to control their cancer. For this reason, it is critical that myeloma patients have equal access to ALL treatments, orally administered and intravenously or subcutaneously (injected) administered drugs. It is also important to note that the two orally administered targeted therapies DO NOT have IV equivalents, and therefore isn't a matter of convenience for patients, but a matter of life and death.

Insurance coverage has lagged behind the proliferation of oral anti-cancer medications in particular. Although oral cancer treatments have become more readily available and the standard of care in many

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cases, insurance plans often have extremely high cost-sharing requirements for oral medications. IV chemotherapy is typically covered under a plan's medical benefits, which requires patients to pay an office visit co-payment. Oral chemotherapy is typically covered under a plan's prescription drug benefit, which can require significant co-insurance. Inadequate insurance, which includes plans with high cost-sharing, is a barrier to patients having access to life-saving cancer treatment.

Specific Comments about Essential Health Benefits in New York

Ensuring equal out-of-pocket costs to patients for IV, injected, and orally administered cancer chemotherapy drugs is the IMF's top legislative priority; during the 2011 legislative session, lawmakers in New York approved legislation to require insurance companies to provide this important coverage for patients. The IMF strongly urges New York policymakers to include parity in out-of-pocket costs for oral chemotherapy drugs in the state's Essential Health Benefits package.

The remainder of our comments represents other concerns to ensure that the EHB package in New York meets the needs of individuals with myeloma and other cancers: access to all therapies in a category or class and access to providers.

Access to Therapies

We are very concerned that under the HHS approach, insurance plan prescription drug formularies are permitted to offer only one drug in each category or class. This proposed requirement falls short of Medicare's requirements and is likely to result in inadequate coverage. This requirement also fails to satisfy the ACA requirement that the EHB package be modeled after the typical employer-sponsored insurance plan, which generally covers more than one drug per class or category of drugs. We ask that you require plans to cover all the drugs in each class or category that are covered by the benchmark plan.

There are several reasons for which covering only one drug in each category or class is inadequate for cancer patients. Patients must have access to the most appropriate therapies for their diseases. First, if the one covered drug is not optimal for a particular patient, adverse side effects may result. Moreover, cancer drugs are not interchangeable and individual patients respond differently to different treatments, and frequently cycle through several regimens during the course of treatment. Also, it is critical that commonly prescribed off-label uses for cancer treatment are included in the EHB package. Off-label anti-cancer drugs are currently covered under Medicare Part D, if the use is supported in designated compendia. Finally, the emergence of personalized medicine and the increasing use of targeted cancer therapies mean that some treatments will only be effective for patients with a particular genetic profile or if their diseases have a particular molecular profile.

If only one drug in a class or category is available, myeloma patients will be limited in their covered treatment options and may not have access to the most effective treatments. Therefore, the IMF believes strongly that all appropriate therapies must be covered, and more than one drug in a class must be available.

Access to Providers and Comprehensive Services

Individuals with myeloma need access to comprehensive diagnostic and treatment services, including a written care plan and all elements of multi-disciplinary care. This care may not perfectly correlate to a broad EHB "bucket" such as hospitalizations or ambulatory services. This multi-disciplinary care includes injectable and oral anti-cancer drugs, stem cell transplants and clinical trials for appropriate candidates. EHB must require adequate networks for cancer patients that include Commission on Cancer-accredited

programs and/or NCI-designated cancer centers or care by out-of-network physicians and other health care providers, if in-network care does not meet the medical needs of the patient. Finally, individuals with myeloma and their families must have access to supportive care, symptom management, and palliative care from the time of diagnosis and across the continuum of care, including but not limited to services provided through hospice.

Conclusion

IMF believes that all cancer patients should have access to the anti-cancer regimens recommended by their physicians and should not be forced to choose a less appropriate treatment option simply because of inordinate out-of-pocket costs for a more appropriate type of therapy or mechanism of delivery. To that end, a well-designed EHB package must provide balanced coverage for all aspects of cancer treatment from preventive care to diagnostic tests to treatment options such as targeted therapies and stem cell transplants to palliative care. Balanced coverage is central to efforts ensuring that health reform reaches its potential to allow Americans to diagnose and to treat cancer and other diseases, improve health, and bend the cost curve.

If you have any questions or need further information about how to ensure that EHB meets the needs of patients with myeloma and their families, please contact Zina Cary, National State Affairs Consultant for the IMF at 540-247-7499.

Sincerely,

Susie Novis

Susie Novis
President, International Myeloma Foundation

In summary, the International Myeloma Foundation (IMF) strongly urges that New York's benchmark plan include the following:

1. Affordable access to procedures standard to the treatment of multiple myeloma including stem cell transplant and radiation therapy.

2. Access to oral and intravenously (IV) administered chemotherapy that includes affordable, equal out-of-pocket expense to patients.

3. Allows patients to seek treatment at National Cancer Institute (NCI) Cancer Centers.

4. Provide coverage of "routine patient care" during participation in cancer clinical trials until the federal requirement takes effect in 2014.

5. Diagnostic services using all available evidence-based technologies.

6. Individual, comprehensive cancer planning that is communicated by health care professionals both orally & in written form.

7. Drugs and biologicals, both physician & self-administered and off-label uses, according to the evidence-based standards utilized in the Medicare program.

8. Prescription drug benefit with full coverage of the six protected classes, offering more than one drug per class, modeled after the Medicare Part D program and a patient appeals process.

9. Palliative & hospice care.

The IMF looks forward to working with New York policymakers as they move forward with determining the states EHB to ensure it is comprehensive in scope & meets the needs of all cancer patients.

For more information, please contact Zina Cary @ zcary@myeloma.org or via phone @ 540-247-7499.