



November 5, 2014

The Honorable Fred Upton
Chairman, U.S. House Energy and Commerce
Committee
2183 Rayburn House Office Bldg
Washington, D.C. 20515

The Honorable Ron Wyden
Chairman, U.S. Senate Finance Committee
221 Dirksen Senate Office Bldg
Washington, D.C., 20510

The Honorable Henry A. Waxman
Ranking Member, U.S. House Energy and
Commerce Committee
2204 Rayburn House Office Building
Washington, DC 20515

The Honorable Orrin G. Hatch
Ranking Member, U.S. Senate Finance
Committee
104 Hart Office Building
Washington, DC 20510

Dear Chairmen Upton and Wyden and Ranking Members Waxman and Hatch,

As you consider the role of managed care plans in the Medicaid programs, please take the needs of medically complex, rare disease populations into consideration when determining best practices for this major shift in Medicaid coverage.

Cystic fibrosis (CF) is a rare genetic disease affecting about 30,000 children and adults in the United States. It causes thick, sticky mucus to clog patients' respiratory, digestive and reproductive systems, and the average life expectancy for those with CF is in the early 40s. CF is a complex, multi-system disease, and people with cystic fibrosis benefit from highly specialized, individualized care provided by a multi-disciplinary team of providers. Highly specialized care promotes greater quality of life, has the potential to help those with cystic fibrosis live healthier lives and may reduce the need for costly hospitalizations.

As many states switch their Medicaid programs from fee for service to managed care, cystic fibrosis patients increasingly encounter burdensome barriers to coverage in all elements of their care. In preparation for this transition, the CF Foundation has initiated discussions with several state Medicaid programs to talk about the needs of CF patients as well as best practices found in the patient-centric care displayed by our network of accredited cystic fibrosis care centers. These conversations with state programs provided a better understanding of the challenges faced as states go through this transition and have opened the doors for collaborative learning and partnership to break down the barriers to coverage for cystic fibrosis patients as well as other rare disease populations.

National Office

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While the following examples provide insight specific to the cystic fibrosis community, they provide an overview of the coverage burdens faced by many rare disease populations and many others requiring complex, coordinated medical care.

Prior Authorization Requirements

Prior authorization requirements often do not reflect the latest evidence-based care guidelines and frequently result in delays in access to physician prescribed care. We ask that Medicaid program administrators work together with Medicaid managed care organizations and CF experts to reduce burdens on CF patients seeking coverage for care and medications that are critical to maintaining optimal health status.

Exclusion of CF Care Centers and Medications from Provider Networks

The classification of CF care centers and specialty CF medications as “out of network” serves as an additional roadblock to obtaining care because this can make treatment prohibitively expensive and out of reach for some patients. Medicaid programs should designate specialized CF care and treatments as “in network” so that patients are not denied the care that gives them the best chance at health and quality of life.

CF care centers are able to maintain a high standard of care in part because the personnel at the centers work with people with CF on a daily basis and have firsthand knowledge of their health care needs. Care center personnel also confront coverage and payment issues along with their patients. This model allows patients to find high quality, specialized care in the context of a patient-centric medical home where care center employees are able to address all aspects of CF patient health care needs. The Cystic Fibrosis Foundation, which funds and accredits these centers, provides tools and resources like the annual North American Cystic Fibrosis Conference, an award-winning Quality Improvement initiative, the CF Patient Registry, which allows for data comparisons between centers, workshops and educational materials to ensure the highest standard of care based on the latest published medical information and research.

Divergent Procedures Across Different Managed Care Programs

The arsenal of drugs available to CF patients is very limited, therefore it is critical that Medicaid preferred drug lists (PDLs) be inclusive of the medications that those with cystic fibrosis need to stay healthy. It is imperative that those with cystic fibrosis have access to the treatments they need without unnecessary delays and administrative burdens. Such delays could potentially be more costly for payers due to the risk of exacerbations and other complications.

Furthermore, multiple managed care organizations working within a state may have different procedures, creating a complex coverage landscape for Medicaid beneficiaries with CF and a significant administrative burden for CF providers. State Medicaid programs should coordinate with their managed care contractors to adopt and maintain similar PDLs, thus ensuring all Medicaid beneficiaries have fair and equal access to the medications that they need.

Medicaid Personnel Who Are Unfamiliar with CF and its Standard Treatment

Clinicians in a recent survey reported that many Medicaid representatives are unfamiliar with cystic fibrosis and/or available treatment options; these gaps in knowledge may contribute to the imposition of inappropriate coverage and payment standards. Our discussions with Medicaid officials in several states have afforded us the opportunity to provide education about cystic fibrosis and the need for access to affordable, specialized care through accredited CF care

centers for this population. We hope to continue these valuable discussions with Medicaid programs across the country and ask that Medicaid personnel seek expert opinions when faced with coverage approval decisions for complex, chronic illnesses like cystic fibrosis.

As Medicaid continues to change in this evolving health care landscape, the Cystic Fibrosis Foundation seeks to expand discussions with Medicaid managed care officials in order to help ensure access to clinically appropriate therapies and care. We are happy to discuss this matter with you further and provide clinical expertise on the needs of patients with cystic fibrosis. Please feel free to reach out to us as a resource.

Thank you for your consideration.

Sincerely,

A handwritten signature in black ink, appearing to read "Robert J. Beall". The signature is written in a cursive style with a large, prominent initial "R".

Robert J. Beall, Ph.D.
President and Chief Executive Officer