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August 16, 2010

Office of Consumer Information
And Insurance Oversight
Department of Health and Human Services
Attention: OCIO-9991-IFC
Post Office Box 8016
Baltimore, MD 21244-1850

RE: OCIO-9991-IFC

Dear Sir or Madam:

The Cystic Fibrosis Foundation appreciates the opportunity to comment on the interim final rules for health plans to retain grandfathered status under the Patient Protection and Affordable Care Act. We offer recommendations for modifications in the regulations that would respond to the needs of individuals with genetic diseases that pose serious health challenges and require complex daily care.

In establishing grandfathered health plans and making them subject to some but not all of the statute's reforms, the Affordable Care Act "balances its objective of preserving the ability to maintain existing coverage with the goals of expanding access to and improving the quality of health coverage." In drafting the implementing regulations, the Departments of Health and Human Services, Labor, and Treasury confronted a significant challenge in providing plan sponsors and issuers flexibility to avoid premium increases while at the same time achieving the goal of ensuring that individuals who like their healthcare can keep it. We think the regulations significantly achieve that balance, but we would recommend some modifications.

Prohibition against Eliminating Benefits for a Particular Condition and Prohibition Against Eliminating Any Element of Care

We strongly support the rule that would prevent a plan from eliminating benefits for any particular condition. The preamble to the interim final rule gives the example of a plan eliminating all benefits for cystic fibrosis as an action that would result in loss of grandfathered status. We applaud the recognition in the rule of the burden that would be borne by those who are diagnosed with and being treated for orphan diseases if plans could eliminate benefits for such diseases. The language of the rule clearly establishes that such action would trigger loss of grandfathered status.

Another critical part of the rule is that provision establishing that plans would use lose grandfathered status by eliminating benefits for any element of treatment for a condition. The treatment of cystic fibrosis is multi-disciplinary and includes management of many separate and distinct symptoms of the disease. Curtailing access to any part of the

management of cystic fibrosis could be devastating to the health care of those living with and managing the disease.

Impact of permissible increases in cost-sharing amounts

We understand that the departments were attempting to provide sponsors and issuers flexibility by allowing them in the initial year under the rule to increase fixed-amount copayments by either 15 percent plus medical inflation or five dollars increased by inflation. However, these increases in deductibles, copayments, or out-of-pocket maximums would represent a substantial financial burden for those with chronic illnesses. Individuals would face a daily and monthly problem in managing the cost of care and related out-of-pocket expenditures and might also face a burden in terms of increased annual out-of-pocket maximums. We recommend a reduction in the percentage increase that would be permitted, above medical inflation.

Notice to consumers regarding the protections provided by grandfathered plans

The departments indicate that grandfathered plans will be required to inform participants and beneficiaries that the plan or coverage is “grandfathered” and must provide contact information for questions and complaints. The departments also ask for guidance about possible improvements in the language provided to consumers.

We recommend that the notice to consumers include details about the protections in the Affordable Care Act that are not applicable to grandfathered plans, the protections of the Act that are applicable to grandfathered plans, and the standards that grandfathered plans must meet to maintain such status. This is a significant amount of detail for consumers, but we think it is a necessary part of the broad educational effort that the departments have undertaken to clarify the scope of the Affordable Care Act.

Changes to prescription drug formulary

The departments seek specific input regarding the inclusion of changes to a prescription drug formulary on the list of changes that might cause loss of grandfathered status. We recommend that the departments define the scope of changes in a prescription drug formulary that would trigger loss of grandfathered status. For individuals with CF, the exclusion of specific drugs or categories or classes of drugs or the employment of aggressive formulary management tools might cause the plan to be altered to a degree that it would no longer represent the “healthcare the consumer wishes to keep.” If a plan were allowed to add categories or classes of drugs to formulary specialty tiers, those drugs might be beyond the reach of consumers.

Changes to a plan’s provider network

For individuals with CF, access to specialists with significant experience and training in CF care and continuity of care are critical to good outcomes. If plans are allowed to retain their grandfathered status while still making substantial changes in their provider network, those with CF may find that they no longer have access to the health care professionals with expertise in their disease. In the difficult balancing that the departments are undertaking, flexibility for plans and issuers is balanced against access to care and maintenance of quality care. However, by failing to address the issue of the provider network changes that grandfathered plans will be permitted to make, the

departments have abandoned their attention to quality for those with serious and life-threatening illnesses that require specialty care of high quality on a daily basis.

The departments are to be commended for developing solid, workable, and flexible standards for health plans and insurance plans to meet in order to retain their grandfathered status. Although significant effort has been made to achieve balance in the approach to grandfathered plans, we urge some changes to ensure that grandfathered plans are offering consumers the health care that they wish to keep. We would recommend more modest allowable increases in fixed-amount copayments, limits on changes to the provider network or prescription drug formulary, and more aggressive notice to consumers regarding grandfathered plans.

Sincerely,

A handwritten signature in black ink, appearing to read "Robert J. Beall". The signature is fluid and cursive, with the first name "Robert" being the most prominent part.

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

National Office

6931 Arlington Road Bethesda, Maryland 20814
(301) 951-4422 (800) FIGHT CF Fax: (301) 951-6378 Internet: www.cff.org E-mail: info@cff.org