



| Adding *tomorrows* every day. \_\_\_\_\_

October 4, 2010

The Honorable Kathleen Sebelius  
Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Re: OCIO-9989-NC

Dear Secretary Sebelius:

The Cystic Fibrosis Foundation (CFF), which invests in the development of new therapies for cystic fibrosis (CF), supports a nationwide system of CF care centers and provides education and support services to those with CF and their families, appreciates the opportunity to comment on the standards for establishment of the American Health Benefits Exchanges (Exchanges) that are authorized by the Patient Protection and Affordable Care Act. We are pleased that the Department of Health and Human Services (HHS) is seeking public input regarding the Exchanges in advance of rulemaking, and we look forward to offering additional advice during the rulemaking process.

Individuals with CF need sophisticated and multi-disciplinary care throughout their lifetimes. Our comments reflect those needs by focusing on strategies to ensure participation by high-value plans in the Exchanges and communication plans for conveying to CF patients and their families their health insurance enrollment options.

Our recommendations to the Secretary are summarized here and discussed in more detail below.

- Ensure appropriate specialists are included in qualified health plans (QHPs) by relying on the advice and accreditation programs of organizations like the CF Foundation, professional societies, and other experts.
- Implement a national plan rating system that utilizes existing quality measurement systems and is responsive to the needs of special populations, including those with rare diseases like CF.
- Allow the establishment of specialized Navigators for public education and enrollment assistance in order to reach populations with special health needs.
- Ensure the coordination of eligibility and enrollment in Medicaid, CHIP, and Exchange plans.

**National Office**

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

We understand that HHS and the Exchanges face a difficult challenge of ensuring participation by high-value plans in the Exchanges while at the same time ensuring participation by an adequate number of plans to guarantee that the Exchanges function well and meet the insurance needs of consumers. Our comments recognize the need to achieve that balance.

### *Qualified Health Plans*

The health care needs of those with CF are complex, requiring the involvement of a wide range of health care professionals and the delivery of many different services. The CF Foundation, through a network of CF care centers, has developed a system for delivery of care and set CF care quality standards. These initiatives ensure that those with CF consistently receive care of high quality.

A major concern for those with CF is access to the appropriate specialists in CF care through Exchange plans. If the qualified health plans (QHPs) included in the Exchanges are inadequate in the number and types of providers who provide CF care, the QHPs will not offer those with CF meaningful insurance coverage.

The HHS Secretary is given authority under the Affordable Care Act for implementing procedures for the certification, recertification, and decertification of QHPs. To guarantee that QHPs offer meaningful coverage options to those with CF, as well as those with other serious and life-threatening illnesses, we recommend that the Secretary rely on recommendations and advice from organizations like the CF Foundation, professional societies, and other experts regarding the kinds and number of providers who should be included in QHPs.

### *Quality and Health Plan Ratings*

We recommend that the Secretary develop a plan rating system and encourage its adoption across the Exchanges. Although the state-based system for implementation of the Exchanges will make coordination across the states challenging, we urge such a national effort. As noted above, the CF Foundation has developed quality measures for CF care, and many other entities have undertaken comparable efforts in their areas of care. We recommend that these quality measurement systems be utilized in the development of a plan rating system that would be responsive to the needs of special populations, including those with rare diseases like CF

### *Navigators*

Under the Affordable Care Act, the Exchanges are given responsibility for establishing grants programs for Navigators to conduct public education activities, distribute enrollment information, facilitate enrollment, and provide referrals for grievances, complaints, or questions. It will be necessary for the Exchanges to rely heavily on Navigators in order to reach populations with special health needs and to provide information in a manner that is culturally and linguistically appropriate.

We encourage the Secretary to establish regulatory standards that would encourage the use of Navigators for a wide range of patient activities and that would also embrace an expansive view of those groups that might provide navigation services. We recommend that community-based organizations, research and professional organizations, and patient advocacy organizations be considered among those that might receive Navigator grants. In addition, we would encourage standards that would anticipate Exchange grant awards to multiple Navigators for each Exchange, with the Navigators potentially assuming responsibility for outreach to specific populations with special health needs.

*Coordination of Medicaid, CHIP, and Exchange Plans*

Those with CF often have a complicated course through the health insurance system, enjoying coverage from many difficult insurers, including Medicaid and CHIP, over a lifetime. For these individuals, the coordination of eligibility and enrollment in Medicaid, CHIP, and Exchange plans is critically important. Even a modest interruption in insurance coverage can result in gaps in care that in turn affect health status. For those with CF, whose adherence with a rigorous daily regimen of care directly affects their health status, no interruption of insurance coverage is tolerable.

It is possible that the Navigators that are funded by the Exchanges could play a role in the coordination of Medicaid, CHIP, and Exchange coverage.

\*\*\*\*\*

The CF Foundation appreciates the opportunity to comment on the standards for establishing the Exchanges.

Sincerely,

A handwritten signature in black ink, appearing to read "Robert J. Beall". The signature is fluid and cursive, with a prominent loop at the end.

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