National
MPS
Society
Support for Families. Research for a Cure.

August 10, 2010

Office of Consumer Information and Insurance Oversight
Department of Health and Human Services
Attention: OCIIO-9994-IFC
Mailstop C4-26-05
7500 Security Boulevard
Baltimore, MD 21244-1850

Re: File Code OCIIO-9994-IFC

Dear Sir or Madam:

The National MPS Society appreciates this opportunity to comment on the Interim Final Rule with Request for Comments entitled "Patient Protection and Affordable Care Act; Requirements for Group Health Plans and Health Insurance Issuers Under the Patient Protection and Affordable Care Act Relating to Preexisting Condition Exclusions, Lifetime and Annual Limits, Rescissions, and Patient Protections" (Final Rule and Proposed Rule).

The National MPS Society exists to find cures for MPS and related diseases. We provide hope and support for affected individuals and their families through research, advocacy and awareness of these devastating diseases.

Our comments on the Interim Final Rule with Comments are focused on annual limits and the definition of "essential health benefits".

Annual limits

Recommendation: The Secretary of HHS should use its authority to establish higher minimum annual limits for persons with rare genetic disorders.

We are pleased that the Agency has established minimum individual annual benefits, and that the dollar amounts increase over the timeframe of 2010-2014. Persons with rare genetic disorders may have exceptional medical needs and incur costs that exceed the limits you outline in this Interim Final Rule. When these persons exceed their annual limit, they often cannot afford life sustaining medical care. Persons with rare diseases then find themselves in untenable situations- in that their pre-existing condition makes it

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impossible to switch insurers or go without care in order to qualify for the temporary high risk pool. Therefore, we ask that you utilize your discretion to establish higher annual limits for persons with rare genetic disorders.

Essential Health Benefits

Recommendation: The Secretary of HHS should establish a transparent process and establish a meaningful definition of "essential health benefits."

Lifetime and annual limits apply to 'essential health benefits" only. The Interim Final Rule states, "These interim final regulations define "essential health benefits" by cross-reference to section 1302(b) of the Affordable Care Act and applicable regulations. Regulations under section 1302(b) have not yet been issued." Section 1302(b) permits the Secretary to establish "at least" the categories specified in the Act. We urge the Secretary to establish a transparent process to define "essential health benefits" and promptly establish its definition of "essential health benefits".

The standard of care, and often the only available treatment for persons with rare genetic and metabolic disorders may include services and items that would only be covered under an expanded definition of "essential health benefits." We welcome the opportunity to engage in dialog with HHS to ensure that these services and items critical to the medical management of persons with rare genetic disorders are considered "essential health benefits" subject to the array of protections under the Accountable Care Act.

In summary, the Accountable Care Act provides the foundation for health care access for all Americans. We ask the Secretary to be mindful and use its discretion to ensure the needs of persons with rare genetic disorders are protected in its implementation of this important law.

Please do not hesitate to contact us with any questions regarding these comments.

Sincerely,

Barbara Wedehase, MSW, CGC
Executive Director