

August 6, 2010

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

Re: File Code OC110-9994-IFC

Dear Sir or Madam:

Genetic Metabolic Dietitians International (GMDI) 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 and Affordable Care Act Relating to Preexisting Condition Exclusions, Lifetime and Annual Limits, Rescissions, and Patient Protections"

GMDI is a non-profit professional organization for registered dietitians specializing in the care of patients with rare metabolic genetic disorders. The mission of GMDI is to "provide standards of excellence and leadership in nutrition therapy for genetic metabolic disorders through clinical practice, education, advocacy, and research. GMDI members are leading practitioners in nutrition therapy who have joined together to identify education and training needs and to develop standards of practice in this highly specialized field. Membership provides opportunities for professional education and research, as well as networking and peer support" <http://www.gmdi.org/>

Our comments are focused on annual limits and essential health limits.

Annual Limits

GMDI' recommends that the Secretary of HHS use her authority to establish higher annual limits for patients with rare genetic disorders.

While we are pleased that the Agency has established minimum annual benefits for individuals, and that the dollar amounts increase over the period of 2010 – 2014. Our concern is that patients with rare genetic disorders may have exceptional medical needs and incur costs that exceed the limits you outline in this Interim Final Rule. If these patients exceed their annual limit, they often cannot afford life-sustaining medical care. Their pre-existing condition makes it impossible to switch insurers or go without

care in order to qualify for the temporary high risk pool. We request that you use your discretion to establish higher annual limits for these patients.

Essential Health Benefits

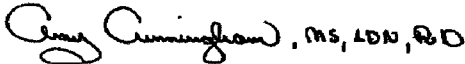
GMDI recommends: The Secretary of HHS establish a transparent process of providing meaningful definitions of "essential health benefits" for patients with rare genetic disorders

Lifetime and annual limits apply to "essential health benefits" only. The Interim Final Rule states that, "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 to promptly employ this definition.

The standard of care, and often the only available treatment, for patients with rare genetic disorders may include services and items that would only be covered under an expanded definition of "essential health benefits." We welcome any opportunity to engage in dialog with the HHS to help define these services and items, critical to the medical management of patients with rare genetic disease, so that they will be protected under the Accountability Care Act.

The Accountability Care Act provides the foundation for health care for all Americans. Members of GMDI are asking the Secretary to consider that, sometimes, extraordinary health care services are necessary to provide a quality of life for those Americans with rare genetic disorders. We are ready to provide further information should you need it.

Sincerely,

Handwritten signature of Amy Cunningham in cursive, followed by the text ". MS, LDN, RD".

Amy Cunningham, MS, LDN, RD, President
GMDI Board of Directors