



**Fatty Oxidation Disorders
Family Support Group**
www.fodsupport.org

**FOD
Family Support
Group**

Deb Lee Gould, MEd, Director
MCAD Parent and Grief Consultant
*Grief Support for Bereaved Parents and
Families*

PO Box 54
Okemos, MI 48805-0054
Office/Cell: 517.381.1940
Fax: 866.290.5206

Email: deb@fodsupport.org
Website: www.fodsupport.org
Federal Tax ID # 83-0471342

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FOD Parent, Director, and President

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August 16, 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

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Re: File Code OCIIO-9994-IFC

Dear Sir or Madam:

The FOD (Fatty Oxidation Disorders) Family Support Group 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 FOD Group's Mission is to connect and network with FOD Families and Professionals around the world and to provide emotional/grief support, Family Stories, practical information about living with these disorders, and Medical Updates to inform families of new developments in screening, diagnosis, research and treatment. We also advocate for issues that directly affect our Families, such as health care and insurance costs.

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

The FOD Family Support Group is an all Volunteer Family-based Group and a tax-exempt 501c3 Non-Profit Corporation

Donations are tax-deductible

Thank you to all that have donated over the years so that we may continue to provide our support and information to Families and interested professionals around the world. Donations help with copying and postage costs, phone calls to new FOD Families (US and abroad), website fees, Conference costs, as well as to provide for grants for future clinical and research activities by our FOD professionals.

Please make US checks out to: FOD Family Support Group and Mail to: PO Box 54 Okemos, MI 48805-0054

THANK YOU from ALL of us!

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 impossible to switch insurers or go without care in order to qualify for the temporary high risk pool. We have had several Families in that situation! 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,

Deb Lee Gould, MEd, Director
FOD Family Support Group
deb@fodsupport.org
Okemos, MI

Digitally signed by Deb Lee Gould, MEd,
Director
DN: cn=Deb Lee Gould, MEd, Director,
o=FOD Family Support Group, ou,
email=deb@fodsupport.org, c=US
Date: 2010.08.22 13:52:22 -04'00'



Deb Lee Gould, MEd
Director, FOD Family Support Group