



**National
Multiple Sclerosis
Society**

August 27, 2010

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Employee Benefits Security Administration
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Washington, DC 20210
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Office of Consumer Information & Insurance Oversight
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RE: 26 CFR 54.9815-2704T, 29 CFR 2590.715-2704, 45 CFR 147.108, 26 CFR 54.9815-1251T, 29 CFR 2590.715-1251, 45 CFR 147.140, 26 CFR 54.9815.2712T, 29 CFR 2590.715-2712, 45 CFR 147.128.

Interim Final Rules for Preexisting Condition Exclusions, Lifetime and Annual Limits, Rescissions and Patient Protections

Dear Sir or Madam:

The National Multiple Sclerosis Society (NMSS, the Society) welcomes this opportunity to provide comments on this Notice of Proposed Rulemaking regarding provisions of the Patient Protection and Affordable Care Act (ACA, the Affordable Care Act). Overall, we are very supportive of the proposed rules as contemplated, and offer the following comments to highlight only those issues of greatest relevance and concern to the approximate 400,000 people in the United States living with a diagnosis of multiple sclerosis.

MS is an often disabling, autoimmune disease affecting the central nervous system. Although there is no cure for MS, access to appropriate medical treatment can slow the disease progression, reduce the frequency and intensity of flare-ups, and allow people with MS to live active and productive lives. Symptoms may be mild, such as numbness in the limbs, or severe, such as paralysis or loss of vision. Other symptoms include fatigue, dizziness, pain, decreased cognitive function and spasticity.

The mission of the NMSS is to mobilize people and resources to drive research for a cure and to address the challenges of everyone affected by MS. Affordable, accessible health coverage is an extremely important component of necessary supports for individuals affected by MS, including people with the disease and their family members. Our nationwide network of activists strongly supported meaningful health insurance market reforms in the ACA, and looks forward to new consumer protections making coverage and benefits more valuable and easier to utilize.

Prohibition of Preexisting Condition Exclusions (2590.715-2704)

The National MS Society strongly supports interim rules that prohibit both the exclusion of children under age 19 from the insurance marketplace due to their health status or history, and the imposition of pre-existing condition exclusions in their health plans. We were relieved when the Secretary acted swiftly to clarify that the law's prohibition against pre-existing conditions for children was intended to stop both of these discriminatory insurer practices. These formerly legal forms of discrimination have become increasingly catastrophic for many families in the MS community in recent years, as the prevalence of MS in children as young as age three have been identified. It is now estimated that an approximate 10,000 children in the US under the age of 18 have MS and another 10,000 to 15,000 experience disorders that may be related to MS.

We believe that expanding and strengthening the HIPAA rules relating to preexisting condition exclusions is an essential first step in ending this kind of discrimination. Because the HIPAA definition of 'pre-existing condition' and its application to health plans remains in effect, it is especially important for consumers (and parents in particular) to understand these definitions and rules.

We are very concerned about the real possibility of plans charging unreasonable premiums for children with pre-existing conditions. Absent meaningful protections against rating based on health status, families with children with pre-existing conditions could continue to experience profound barriers to coverage and care. The Secretary's anticipated definition of 'unreasonable' premiums and new procedures for reviewing insurers' rates should include documentation about rate increases that are applied to policies that cover children. Regulations should require reporting on the number of children under age 19 that were added to the subscriber's coverage, as a result of the new law.

Lifetime and Annual Limits (2590.713-2711)

The National MS Society applauds the interim final rules that prohibit health plans from imposing lifetime limits on benefits. The annual health care costs per case of MS are currently approaching \$40,000, and the total number and rate at which insured persons with MS are outliving their health insurance is accelerating. This long overdue protection against the devastating loss of coverage cannot come too soon for families coping with MS.

Enrollment After Lifetime Caps

Clarification in the final rules is recommended regarding which former plan enrollees are eligible to re-enroll under the prohibition on lifetime limits, particularly in the individual market. Additionally, the final rules should address premium rate-setting for those that have previously reached a lifetime limit, specifying that no new underwriting or claims history may be used when determining a premium for coverage for such individuals.

To assure consumers are made aware of this protection, the notice about new enrollment opportunities for those that have already reached their lifetime limit should be provided in plain language, with clarification regarding the beginning and end of the 30 day special enrollment period.

Good Faith Efforts re: Annual Limits

We are similarly concerned about new protections against annual dollar limits on essential benefits and strongly recommend the regulations be strengthened. Even before the essential benefits are defined, it is critically important that “good faith efforts” to provide anticipated essential benefits be clearly articulated and enforced.

While the interim final rules advise health plans to use “good faith efforts” to determine the meaning of “essential benefits,” the ambiguity may lead to significant variations in the set of benefits subject to the rule. The rules should provide an objective definition of “good faith efforts.” Loss of grandfathered status alone is not sufficient to discourage plans from decreasing their existing benefit packages to adjust for bans in lifetime and annual limits.

The regulations should be consistent with evidence-based guidelines developed by experts such as voluntary health organizations, professional medical societies, and consumer advocates. Furthermore, the standard for coverage should not be limited to a strict adherence to guidelines based on published evidence, which have in the past resulted in denials for coverage of high quality care. Where evidence is lacking, as is often the case in many areas of complex, chronic conditions, the consensus recommendations of clinical experts should suffice as a standard for coverage.

We are concerned that non-monetary limits on benefits may still be allowable, such as numeric limits on items or services which could effectively result in the same caps on coverage and access limits on medically necessary care as dollar limits. This is especially true among self-insured plans that are not subject to the same market conduct reviews as fully-insured plans. Instead of allowing arbitrary caps, the rules should clarify that medical necessity is the criteria upon which insurers must base their claim determinations.

Waiver of Annual Limit Restrictions for Certain Health Plans

The rules provide that the Secretary of Health and Human Services may grant a waiver from annual limit restrictions to plans for which the application of the

requirements “would result in a significant decrease in access to benefits or a significant increase in premiums.” The rules state that future guidance will be provided on the scope and process of such a waiver. Such future guidance should clarify what is meant by “a significant decrease in access to benefits” and should also include specific criteria for what qualifies as a “significant increase in premiums.” Guidance should further provide for public notice and comment on proposed waivers and the posting of granted waivers on the internet.

The preamble to the rules discusses mini-med plans as being possibly subject to future waivers. While we understand the need to protect people who have already enrolled in these policies until they have access to another affordable plan in 2014, we are concerned that many consumers enroll in these plans without understanding how unprotected they are against major medical expenses. Consumers in these plans have found themselves without access to care and/or in debt when they experience illness. The Secretary should consider whether consumers are likely to get anything of value for their premium for a mini-med policy before granting a waiver. If waivers allow new enrollments in these plans at all prior to 2014, the Secretary should require prominent warnings to consumers and employers, including information on what essential benefits are not covered or are limited and information about how to find more comprehensive coverage

Applicability of Annual and Lifetime Limits to Student Health Plans

Although rules regarding student health plans have yet to be issued, we share the concerns expressed by other advocates about the need for equally strong and clear consumer protections for insurance coverage of this vulnerable group. The Patient’s Bill of Rights should expressly apply to student health plans. Further, when evaluating waivers from annual caps for those plans, the Secretary should carefully consider the consequences of withholding this basic protection from students on plans with minimal benefits.

Prohibition on Rescissions (2590.715-2712)

The National MS Society supports the interim final rules that prohibit health plans from rescinding coverage except for fraud or intentional misrepresentation. MS can be difficult to diagnose, and it is not unusual for individuals to be diagnosed with one or more other conditions incorrectly before a proper diagnosis is made. Similarly, the signs of symptoms of MS often mimic those of other conditions, and some have been diagnosed with MS only to be relieved later on to learn they had less severe, and even entirely curable conditions.

In the past, people who have experienced MS- like symptoms but do not have a diagnosis of definite MS have omitted information from medical questionnaires and insurance applications with no malicious intent, and others have avoided care and coverage for fear of the consequences of such disclosures. For these reasons, our community is particularly sensitive to allegations of ‘fraud’ or ‘misrepresentation’, and strongly supports clear and enforceable regulations and definitions in support of this provision.

While we support the interim final rules, we believe that the rules could be strengthened in the following ways:

- The interim final rules only allow for rescission under certain circumstances (i.e. fraud or intentional misrepresentation); however, the rules should allow for any rescission to be reviewed by an independent third-party. In addition, health plans should be required to continue coverage during the review and appeal process, even if the 30 day notice period has expired.
- The interim final rules should provide greater guidance on the notice and appeals procedure. For example, any notice should be required to be in writing and contain all relevant information to the investigations (i.e. when the investigation began, the disputed information, and the plan holder's right to appeal). Additionally, plan holders should have the opportunity to offer relevant evidence to the insurer within a reasonable time frame.
- The rules should allow a health plan to investigate a potential omission or misrepresentation only if it can prove to the state that it has reasonable grounds to suspect that the enrollee intentionally omitted or misrepresented information during the application process.
- The Secretary should establish standardized information and health history questions to be used on health plan application forms. Standardized information will provide greater uniformity for what is often long and confusing paperwork.
- The term "material fact" needs clarification and should be narrowly defined. Consumers otherwise may not be clear what information is material to the issuance of a health insurance policy
- The regulation should explicitly note that insurers bear the burden of proving that a consumer has committed fraud or intentional misrepresentation of a material fact. Consumers should be informed that the insurer bears the burden of proof in the 30-day advance notice of rescission that plans must provide.

Patient Protections (2590.715-2719A)

The National MS Society also strongly supports the interim final rules' patient protections allowing consumers greater choice when selecting in-network care providers and pediatricians. We would urge the final rules be strengthened through the following:

- The Secretary should use her discretion to include provisions that would allow patients with disabilities and chronic conditions to have better access to specialty care without prior authorization from a primary care "gatekeeper."

Allowing greater access could improve efficiency, decrease costs to the plan and lead to more timely care.

- The emergency care provisions should be expanded to specifically include in-network services. While the interim final rules provide protections against administrative hurdles and undue cost-sharing for out-of-network emergency services, the rules do not specifically apply the same protections to in-network services.

The National MS Society truly believes that these interim final rules are an important first step for people living with chronic conditions and disabilities, including people living with MS. However, we also believe that the rules, in their current state, could be strengthened to provide even greater protections. We appreciate the opportunity to provide comments on such pressing issues.

Thank you for your consideration.

Shawn O'Neil
Vice President, Federal Government Relations