October 16th, 2014

Dear Ms. Matthews,

We are writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014. The regulations relate to the individual market and small group coverage.

Of great concern to us are section 14(B) of the individual market model and section 15(B) of the small group model both would permit health insurers to exclude from the annual limit “benefits provided out-of-network.” This is inconsistent with statutory language (see ACA section 1302(c)), and may make out-of-pocket protection more or less illusory in light of well-documented concerns with narrow networks. Moreover, the NAIC’s language is broad enough that it could – in theory – be interpreted by plans to excluded benefits covered through an appeal or exception process. This would be a step backward from current practice.

The rare disease community is particularly sensitive to excluding out-of-network benefits from the annual limit. Typically and unfortunately, a large number of providers seen by patients with rare or undiagnosed diseases are out-of-network. As a result, patients with rare diseases are unfairly penalized by this policy interpretation. We are deeply concerned that the current NAIC drafts would erode one of the ACA’s most important consumer protections—the annual limit on out-of-pocket spending.

We are requesting that the drafts remain under discussion in light of our concerns and the critical importance of annual limits on out-of-pocket spending. Furthermore, the draft language is broad enough that it could be interpreted by plans to exclude benefits covered through an appeal or exception process, which is a huge step backward from current practice.

Sincerely,

**Brian McBride**
Brian McBride
Chairperson, GIST Cancer Awareness Foundation