INDIVIDUAL CONSUMER LETTERS ON DRAFT MODEL REGULATIONS
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude 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. I am deeply concerned the current NAIC drafts would erode one of the ACA’s most important consumer protections — the annual limit on out-of-pocket spending. I am requesting the drafts remain under discussion in light of my concerns -- and those of the rare disease community -- based on the importance of annual limits on out-of-pocket spending.

My experience is personal as my husband was diagnosed with Pemphigus Vulgaris and it took approximately three doctor’s and two hospital visits to obtain an accurate diagnosis. All this lost time resulted in my husband being so critical ill, he almost lost his life to this disease. When one is fighting for their lives there is little time to ensure the doctor and hospital are in network and/or out of network. The goal is to save the life of the patient.

Sincerely,

Penney Armstrong

Penney Armstrong

*cell - 602-329-8264*

penney.l.armstrong@intel.com
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

As a member of the rare disease community I am 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. I am deeply concerned the current NAIC drafts would erode one of the ACA’s most important consumer protections — the annual limit on out-of-pocket spending. I am requesting the drafts remain under discussion in light of my concerns -- and those of the rare disease community -- based on the importance of annual limits on out-of-pocket spending.

Sincerely,

Marla Beeson
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model. Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude 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. I am deeply concerned the current NAIC drafts would erode one of the ACA’s most important consumer protections — the annual limit on out-of-pocket spending. I am requesting the drafts remain under discussion in light of my concerns -- and those of the rare disease community -- based on the importance of annual limits on out-of-pocket spending.

Sincerely,

Pola Berggrun
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,

Sharon Binter
Dear Ms. Matthews,

Attached is a photo of my mother in law at John’s Hopkins University Hospital in Maryland suffering from a very rare disease and later died. This legislature is very close to my heart.

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,

Rachel

Rachel Boughter, RN, BSN, CCM
Medical and Catastrophic Case Manager
GENEX Services, LLC
10240 W. National Avenue, Suite 154
West Allis, WI  53227
Mobile:  608-358-2244
Email: Rachel.boughter@genexservices.com
Fax:  877-211-6691
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,

Lori Boyle
Rare Disease Patient
Dear Ms. Matthews,

I suffer with cicatricial pemphigoid disease, and I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,
Jack
John A. Dohme, Ph.D.
Dear Ms. Matthews,

I have a rare disease that currently has no cure and little coverage within health insurance plans. There are treatments and procedures that help make my disease more livable, but depending on the insurance, they may not be covered in-network.

I am writing you to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude "benefits provided out-of-network" from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

The rare disease community, of which I am a member, 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. I am deeply concerned the current NAIC drafts would erode one of the ACA’s most important consumer protections — the annual limit on out-of-pocket spending. I am requesting the drafts remain under discussion in light of my concerns -- and those of the rare disease community -- based on the importance of annual limits on out-of-pocket spending.

Sincerely,

Nevin Dubin
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,

Patricia Eller

Charlotte, NC
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,

Anthony P. Fernandez, MD, PhD
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude 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. I am deeply concerned the current NAIC drafts would erode one of the ACA’s most important consumer protections — the annual limit on out-of-pocket spending. I am requesting the drafts remain under discussion in light of my concerns -- and those of the rare disease community -- based on the importance of annual limits on out-of-pocket spending.

I personally suffer from pemphigus and with the help of a specialist have been able to get it under control. I went undiagnosed for over a year and a half before being led to someone who was able to figure out what I had and prescribe the correct treatment. Before that my health was in a declining state.

My health depends on being under the care of this out of network specialist- the only doctor on the east coast in my area who is knowledgeable about my disease.

Thank you for your consideration in this matter!

Sincerely,

Ann Fischer

126 Brookside Avenue

Cresskill, NJ 07626
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,

Donovon Franco
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
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model. Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude 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. As someone who suffers from a rare disease, I have been directly affected by the “out of network” limit, as all of the doctors who have treated my disease have been “out of network”. It was not until I found an “out of network” doctor who treated my disease in May of 1998, that I was able to get the help I needed. I suffered for 18 months with the disease steadily progressing before I was able to get the proper diagnosis and treatment. I have since had wonderful doctors who know how to treat a rare disease such as mine, but all of them have been ‘out of network”. For this reason, I am deeply concerned the current NAIC drafts would erode one of the ACA’s most important consumer protections — the annual limit on out-of-pocket spending. I am requesting the drafts remain under discussion in light of my concerns -- and those of the rare disease community -- based on the importance of annual limits on out-of-pocket spending.

Thank you for your attention to this matter.

Sincerely,

Lois J Gregory
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,

Gerald Gushiken
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

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I am writing along with others who have rare or have had rare diseases and need specialized treatments that may be out of network or out of pocket expenses may be so excessive that they are out of reach, so those of us continue to struggle and suffer without proper treatment and in some cases experimental and clinical trials...I would urge you to please review the “eroding of one of the ACA’s out-of-pocket spending” protections...this is essential and necessary for our treatment.

Sincerely,

Vicki J. Hopkins

vihop@aol.com

CC: IPPF (International Pemphigus & Pemphigoid Foundation)
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

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Sincerely,

Tom Logan
New Mexico
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

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Sincerely,

Jack Protetch
Director, Stroke Program
Allegheny General Hospital
Allegheny Health Network

Tel: 412.359.6532
jprotetc@wpahs.org
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

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It is difficult enough dealing with such a rare disease with no standard protocol for treatment. I am fortunate enough to have an oral pathologist at the Medical University of South Carolina who is willing to work with me on a trial and error basis to see if we can at least keep this oral mucus membrane Pemphigoid at bay. Please don't cripple my opportunity to find something that works for me.

Sincerely,

Elaine Richardson

M. Elaine Richardson, PhD
Professor and Director Emerita
Academic Success Center
Clemson University
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations related to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,

Debra Rothbard
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,

Avis Simpkins
Dear Ms. Matthews,

I am writing to express my grave concern regarding two model insurance regulations circulated for public comment on September 30, 2014. These regulations relate to individual market and small group coverage.

Of greatest concern are sections 12 (B) of the individual market model and 15 (B) of the small group model, both of which 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 ambiguous 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 as excluding 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...which our agency routinely deals with related to Alzheimer’s disease and related dementias....are out of network.

Families caring for a loved one with Alzheimer’s disease or another form of dementia are already stretched to the limit financially because of this particular group of disease’s lengthy duration and the lack of payment for most of the services these patients require. As a result, dementia patients and others with rare diseases are unfairly penalized by this policy interpretation.

We are deeply concerned that the current NAIC draft 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 too broad and can be interpreted by plans to exclude benefits covered through an appeal or exception process, which is a huge step backward from current practice.

Please feel free to contact me if you have any questions.

Nancy Squillacioti  
Executive Director

Nancy Squillacioti  
Executive Director  
Alzheimer’s & Dementia Resource Center  
1506 Lake Highland Drive  
Orlando, Florida  32803  
Phone: 407.843.1910 x307  
Toll free: 800.330.1910  
Fax: 407.381.4155  
email: nancy@ADRCcares.org  
website: www.ADRCcares.org
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude 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. I am deeply concerned the current NAIC drafts would erode one of the ACA’s most important consumer protections — the annual limit on out-of-pocket spending. I am requesting the drafts remain under discussion in light of my concerns -- and those of the rare disease community -- based on the importance of annual limits on out-of-pocket spending.

Sincerely,

Richard Stachurski

Colonel (Ret.), USAF

*Author of Below Tranquility Base: An Apollo 11 Memoir,*
the story of a history major surrounded by bona fide rocket scientists.
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on
September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude 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. I am deeply concerned the current NAIC drafts would erode one of the ACA’s most important consumer protections — the annual limit on out-of-pocket spending. I am requesting the drafts remain under discussion in light of my concerns -- and those of the rare disease community -- based on the importance of annual limits on out-of-pocket spending.

Sincerely,

Rick Szteinbaum
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude 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. I am deeply concerned the current NAIC drafts would erode one of the ACA’s most important consumer protections — the annual limit on out-of-pocket spending. I am requesting the drafts remain under discussion in light of my concerns -- and those of the rare disease community - - based on the importance of annual limits on out-of-pocket spending.

Sincerely,

Joseph Urban
Stuart, Florida
Dear Ms. Matthews,

As a member of the rare disease community, I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014. Specifically as the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model. I was diagnosed with pemphigus vulgaris recently, a rare blistering autoimmune disorder. Without a specialty doctor, my condition, already life-changing, would have worsened significantly.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude 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. I am deeply concerned the current NAIC drafts would erode one of the ACA’s most important consumer protections — the annual limit on out-of-pocket spending. I am requesting the drafts remain under discussion in light of my concerns -- and those of the rare disease community -- based on the importance of annual limits on out-of-pocket spending.

Trinie Garcia-Valdez
Culver City, CA
Dear Ms. Matthews,

As a member of rare disease community I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model. Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude 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. I am deeply concerned the current NAIC drafts would erode one of the ACA’s most important consumer protections — the annual limit on out-of-pocket spending. I am requesting the drafts remain under discussion in light of my concerns -- and those of the rare disease community -- based on the importance of annual limits on out-of-pocket spending.

Sincerely,

Yelena Varfolomeyeva
Designer
ph. # (516) 223-0772
fax # (516) 223-3775
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relative to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Leslie A. Weiss
Broker Associate
Premiere Plus Realty Co.
370 Twelfth Avenue South
Naples, Florida 34102
leslielovesnaples@mac.com (e-mail)
www.leslielovesnaples.listingbook.com (website)
239-961-1000 (Cell)
Multi-Million Dollar Producer
2014 Five Star Professional Award
Gulfshore Life Top 7% Agent List
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

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Sincerely,

Yvette Nachmias-Baeu

*surviver of a serious rare disease: Pemphigus*. Just because its rare doesn't mean we should be discriminated against. We may be rare but there are still enough of us to warrant your attention and concern. Its important that Congress worked for the people...and concern itself with the suffering of all its constituents.
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,

Richard Berry
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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I specifically am a recognized national expert in pemphigus, pemphigoid and mycosis fungoides which have incidences of all <1-2/100000. Many patients need referral out of network to seek my care and management for these diseases and restriction of this coverage would compromise their health and wellbeing as there are not enough immunodermatology specialists within any of our regional networks who are skilled at managing these conditions.

Sincerely,

David Fivenson, MD
3001 Miller Rd
Ann Arbor, MI 48103
734-222-9630 office
734-222-9631 fax
www.fivensondermatology.com
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

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Sincerely,

Barbara HEE
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,

Marilyn Mahon
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,

Shouna Olson, a person with a rare disease who requires specialized services that are out of network
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Before my diagnosis, I went to numerous doctors then after my diagnosis, it took me quite a while and a trip out of state to ensure I was being treated correctly. With an auto-immune disease this process adds too much stress and becomes very frustrating.

Sincerely,

Suzanne Rohan, Seguin, Texas
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude "benefits provided out-of-network" from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude 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. I am deeply concerned the current NAIC drafts would erode one of the ACA's most important consumer protections - the annual limit on out-of-pocket spending. I am requesting the drafts remain under discussion in light of my concerns -- and those of the rare disease community -- based on the importance of annual limits on out-of-pocket spending.

Sincerely,

Jeni Romero
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude 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. I am deeply concerned the current NAIC drafts would erode one of the ACA’s most important consumer protections — the annual limit on out-of-pocket spending. I am requesting the drafts remain under discussion in light of my concerns -- and those of the rare disease community -- based on the importance of annual limits on out-of-pocket spending.

Sincerely,

Richard M. Seligma
rseligman@Comcast.net
312.865.4746
Dear Ms. Matthews,

As a patient with a rare disease and an attorney, I am extremely concerned about two model insurance regulations circulated for public on September 30, 2014, specifically Section 14(B) of the individual market model and Section 15(B) of the small group model. Both would exclude "benefits provided out-of-network" from the annual limit. This is inconsistent with the language provided in PPACA Section 1302(c) and may make out-of-pocket protection illusory in light of well-documented concerns with narrow networks. Moreover, the NAIC's language is broad enough that in could - in theory - be interpreted by plans to exclude benefits covered through an appeal or exception process.

The rare disease community, of which I am a part of, is particularly sensitive to excluding out of network benefits from the annual limit. Unfortunately, a large number of providers who have the expertise to treat patients with rare or undiagnosed diseases are out-of-network. As a result, patients with rare diseases are unfairly penalized by this policy interpretation.

I am gravely 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. I am requesting the drafts remain under discussion in light of concerns - and those of others in the rare disease community - based on the importance of annual limits on out-of-pocket spending.

Sincerely,

Seema Shah
Dear Ms. Matthews,

As a survivor of pemphigus vulgaris I know only too well the challenges of dealing with a very very rare disease. I spent almost a month in the burn unit at University Hospital in Denver, which was the only medical facility that could deal with my massive skin loss....between 50 and 70% internally and externally in less than 6 weeks!! Only 6 weeks before my body decided to reject my skin, with this rare disease, I was a very healthy happy 57 year old. It took me more than 5 years to be able to regain some normalcy in my life and I continue to deal with the side effects of massive doses of prednisone and immune suppressing drugs, along with the other drugs I needed to take to deal with the many side effects that these suppressive drugs cause. As you may know, sometimes dealing with health insurance companies can be challenging even with simple health issues, so adding to this with complicating “out of network” costs/benefits due to patients need to see a variety specialists for a major life changing rare disease need not be even more challenged and complicated by the additional costs of health care that in most cases like mine would be “out of network”. Please read the information below and be compassionate and caring as you submit this legislation.

Thank you!

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,

Sloan Stevens
Dear Ms. Matthews,

I am writing to express concern with two model insurance regulations circulated for public comment on September 30, 2014 regarding the regulations relate to the individual market and small group coverage. I am extremely concerned with Section 14(B) of the individual market model, and Section 15(B) of the small group model.

Both would exclude “benefits provided out-of-network” from the annual limit. This is inconsistent with statutory language provided in PPACA 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 exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

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Sincerely,

Margaret Temkin
Dear Ms. Matthews,

As a patient with a rare disease, I am writing to express my concern about the two model insurance regulations circulated for public comment on September 30, 2014. These regulations are of special concern as they affect patients like me who need to see specialists who treat my disease and are out-of-network consequently increasing my annual maximum limit. In addition to being affected myself, I also represent a patient community that could be harmed if these policies and it's language remains as it is.

I am writing to express my concern over Section 14(B) of the individual market model, and Section 15(B) of the small group model. Both would exclude “benefits provided out-of-network” from the annual limit. Not only is this inconsistent with statutory language provided in PPACA Section 1302(c) because it could make out-of-pocket protection more or less illusory in light of well-documented concerns with narrow networks, it hurts patients and their families who have yet to be diagnosed, or treat those who have been diagnosed. What's worse is the NAIC’s language could be interpreted by plans to exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

I am requesting that the drafts remain under discussion as the critical importance of annual limits on out-of-pocket spending needs to be revisited because in it's current language the harm that it may cause me and other patients will be irreparable.

Thank you,

Marc Yale
Certified Peer Health Coach