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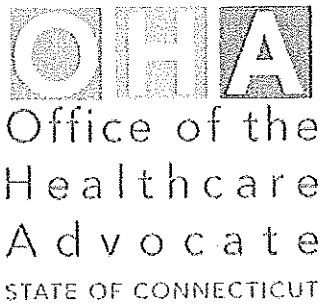


Testimony of Victoria Veltri, Acting State Healthcare Advocate
Before the Insurance and Real Estate Committee
On SB 1158
March 15, 2011

Good afternoon Senator Crisco, Representative Megna, Senator Kelly, Representative Coutu and members of the Insurance and Real Estate Committee. For the record, I am Victoria Veltri, the Acting State Healthcare Advocate. My office, the Office of the Healthcare Advocate (OHA) is an independent state agency with a three-fold mission: assuring managed care consumers have access to medically necessary healthcare; educating consumers about their rights and responsibilities under health insurance plans; and, informing you of problems consumers face in accessing care and proposing solutions to those problems.

Today I testify to point out OHA's concerns with SB 1158, An Act Concerning Utilization Review, Grievances and External Appeals Processes of Health Carriers. While I think the bill is well intended, and contains consumer protections we support, it also contains some serious drafting errors that require further revisions.

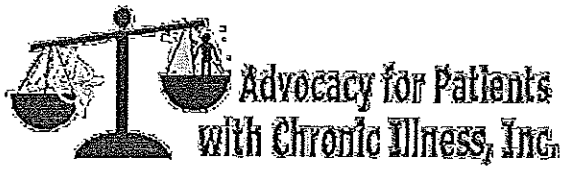
OHA has worked with a coalition of consumer advocates in assisting the federal government to implement internal and external appeals under health care reform. We have participated in a series of conference calls with officials from the United States Departments of Health and Human Services, Labor, and Treasury regarding the formulation of final federal rules on appeals. SB 1158 is one of the pieces of legislation that must be passed in order for Connecticut to comply with federal health reform legislation and interim final rules (IFR). Changes that must be made to Connecticut law are relatively modest, ***although they are of great importance to consumers.*** We have to be certain to get this right.

Every day OHA assists Connecticut consumers in exercising their rights to appeal. To the extent those rights have been positively affected by federal healthcare reform, our laws need to come into compliance.

Rather than re-draft testimony, we attach the March 11th letter of Jennifer Jaff, Executive Director of Advocacy for Patients with Chronic Illness, with which we align ourselves.

We are willing to work with the Insurance Department on revising language to ensure this bill meets the requirements of the IFR.

Thank you for you attention. Please contact me if you have any questions at victoria.veltri@ct.gov or (860) 297-3982.



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March 11, 2011

Senator Joseph J. Crisco
Co-Chair
Insurance and Real Estate Committee
Legislative Office Building
Room 2800
Hartford, CT 06106

Representative Robert W. Megna
Co-Chair
Insurance and Real Estate Committee
Legislative Office Building
Room 2800
Hartford, CT 06106

Dear Senator Crisco and Representative Megna:

I am writing with some sense of urgency regarding Raised Bill 1158, which is scheduled to be heard by the Insurance and Real Estate Committee on Tuesday March 15, 2011. The Bill as drafted has **significant drafting errors** that must be corrected if Connecticut is to comply with federal law. However, this legislation also provides critical consumer protections that we enthusiastically support. Thus, we write now to urge the Committee to ensure that the drafting errors are corrected before this Bill is voted out of Committee to ensure Connecticut's consumers the full protections embodied in federal health reform.

Advocacy for Patients with Chronic Illness provides free information, advice and advocacy services to patients with chronic illnesses nationwide. In particular, we file both internal and external insurance appeals in every State in the country, with both fully-funded and self-funded plans. Indeed, we are one of the few organizations in the United States that files insurance appeals in every State. As such, we have been identified as a national expert in this field, and have been working with a coalition of national consumer advocates in assisting the federal government to implement this aspect of health care reform. We have participated in a series of conference calls with officials from the United States Departments of Health and Human Services, Labor, and Treasury regarding the formulation of final federal rules on appeals. Thus, we are in a unique position to comment in some detail on this legislation.

Raised Bill 1158, which was referred to you only two days ago, is one of the pieces of legislation that must be passed in order for Connecticut to comply with federal health reform legislation and interim final rules (IFR). The federal law and IFR establish a floor for both internal and external appeal from adverse benefit decisions by insurers. For the first time, every State is required to offer external appeal, as Connecticut has done for several years, to the benefit of Connecticut's consumers. Unlike a handful of other States, Connecticut need not start from scratch in that it has required both internal and external appeals for years. The changes that must be made to Connecticut law are relatively modest, although they are of great importance to consumers. We have to be certain to get this right.

We are providing you with our feedback in two parts. First, we are noting substantial drafting errors that must be corrected. Second, we are providing our comments, ways in which the Bill can be improved.

I. The Bill Contains Several Drafting Errors

A. Internal Appeals

Sections 5 and 6 of the Bill pertain to internal appeals. Section 5(b) applies, on its face, only to appeals from denials of coverage due to the insurer's contention that the service in question is not medically necessary. It is unclear whether the remainder of Section 5 pertains only to medical necessity appeals. Section 6 applies, by its terms, to appeals from adverse determinations <u>not</u> based on medical necessity.

The differences between these two sections are stark. For example, Section 5 guarantees the independence of the health insurer's review, requires that clinical peers who are health care professionals with relevant experience conduct the review, that all relevant documents be provided, free of charge, to the consumer upon request, that any new evidence be provided to the consumer before a decision is made on an appeal, as well as detailing the content of the notice of decision. Section 6 has far narrower consumer protections since, it appears, medical judgment is not anticipated to be required for non-medical necessity appeals.

Setting aside, for the moment, the particular provisions of these sections, about which we will provide further comment below, there are several drafting errors in these sections. First, Section 5(b) establishes a 180 day deadline for filing a medical necessity appeal. There is no time frame for filing non-medical necessity appeals.

Second, Section 5(i)(6)(E) refers to both medical necessity appeals and appeals from decisions that a treatment is experimental or investigational. Does that mean that all of Section 5 pertains to experimental/investigational appeals, contrary to the express language of Section 5(b)? In order to comply with federal law, the protections in Section 5 must apply to experimental/investigational appeals, but the mention of ONLY medical necessity appeals in Section 5(b) creates ambiguity on this point.

Thus, to correct these errors, a deadline for the submission of all internal appeals should be provided, which means that such a deadline should appear in both Sections 5 and 6.

Also, and more importantly, Section 5 should clearly and expressly apply to appeals involving any exercise of medical judgment, whether stated in terms of medical necessity or experimental/investigational. The protections contained in Section 5, including the independence of the review, the qualifications of the reviewer, consumer access to the insurer's file, and the content of the appeal decision all pertain equally to experimental/investigational appeals.

Indeed, these protections apply to any appeal involving the exercise of medical judgment. While the procedures set forth in Section 6 may be sufficient for some types of adverse determinations such as rescissions, in which no medical judgment is required, a denial based on medical appropriateness, health care setting, and level of care, along with experimental/investigational denials, all involve the exercise of medical judgment. Section 5 should be clarified to ensure that it applies to all appeals involving the exercise of medical judgment; Section 6 should apply only to adverse benefit determinations that do not involve the exercise of medical judgment, such as rescissions. In the alternative, Section 6 could be omitted entirely and Section 5 could govern all internal appeals. What cannot be allowed to remain is ambiguity about which Section pertains to experimental/investigational appeals and other non-medical necessity appeals that do involve the exercise of medical judgment.

B. External Appeals

The drafting error pertaining to external appeals is even clearer. Section 9 pertains to standard (i.e., not expedited) external appeals of all adverse benefit determinations. Section 10 pertains to expedited external appeals of adverse benefit determinations. Section 11 pertains to <u>expedited</u> external appeals of adverse benefit determinations based on the claim that the service is experimental/investigational. Sections 11(b)(2)(C) and 11(f)(2)(B)-(D) include the language regarding external experimental/investigational appeals found in the National Association of Insurance Commissioners Model Act, section 10, as required by federal law. However, there is no section pertaining to standard (i.e., not expedited) external appeals of experimental/investigational determinations. This is easily corrected by following the NAIC Model Act and eliminating the expedited appeal language from Section 11(a)(1), which we believe most likely was the drafter's intent.

Again, this appears to be nothing more than a drafting error. The NAIC Model Act, which the Affordable Care Act § 2719 provides shall serve as a model for external appeal laws, does not include a separate section on expedited experimental/investigational appeals, nor is a separate section necessary. However, without a section on standard experimental/investigational external appeals, the Bill will not comply with federal law.

II. Comments on the Bill

We now turn to our comments on Raised Bill 1158.

1. The Bill contains a definition of "best evidence" and a separate definition of "medical or scientific evidence." These definitions are different, and we are unsure whether it makes sense to have two different definitions of terms that appear to be used to connote the same type of evidence.

   More importantly, though, the phrase "best evidence" includes expert opinion in the absence of published studies, but the phrase "medical or scientific evidence" does not. This is important, especially in the context of rare diseases, as to which there often is a dearth of published medical literature. We urge you to include expert opinion in the definition of "medical or scientific evidence."

2. In addition, we strongly urge the Committee to consider establishing and defining the phrase "medically appropriate off-label use" as a basis for coverage. In our experience, the vast majority of experimental/investigational denials in fact are denials of coverage of off-label uses of drugs and devices.[1] Rather than process these adverse benefit determinations as experimental uses when, in fact, they may be well-established uses supported by years of clinical practice, the reason for the denial should be stated more accurately, thereby allowing the consumer to focus on the medical appropriateness of the drug or device in the particular case rather than trying to prove that the drug or device is not experimental, which requires medical or scientific evidence. Vermont defines "medically appropriate off-label use of a drug" to mean "the use of a drug pursuant to a valid prescription by a health care provider where the drug is reasonably calculated to restore or maintain the insured's health, prevent deterioration of or palliate the insured's condition, or prevent the reasonably likely onset of a health problem or detect an incipient problem . . . ." Vt. Admin. Code § 4-5-4.7(A)(3). This appears to us to be an easier standard to meet than the experimental/investigational standard in that it can be proven through medical records without extensive medical research, and it is a more appropriate rationale for denial if the drug or device already is FDA approved for one use and it is being prescribed for another use. Thus, we urge adoption of this phrase and the accompanying definition.

3. Section 3(a)(2) states that utilization reviewers must use documented clinical review criteria based on "sound clinical evidence." Section 1(3) defines "best evidence." Section 1(29) defines "medical or scientific evidence." However, there is no definition of "sound clinical evidence," nor is it clear what this means in the context of utilization review. In addition, Section 3(2) provides that the clinical review criteria should be evaluated "periodically." This does not determine the proper frequency of such review.

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[1] An off-label use is the use of a drug or device for a use other than that for which it is FDA approved. To give a simple example, if the approved use of aspirin were to address pain, the use of aspirin to prevent heart attacks would be considered off-label.

In cases involving insurers' claims that a service is experimental or investigational, clinical review criteria form the basis for the denial of coverage. As such, these documents are critical. All too often, they rely only on large-scale clinical trials, without regard for – indeed, even rejecting – the other types of evidence included in the definitions of "best evidence" and "medical or scientific evidence." We urge the Committee to clarify the phrase "sound clinical evidence" to mean either "best evidence" or "medical or scientific evidence." [2]

In addition, we request that the Committee consider requiring that clinical review criteria be evaluated annually. The failure of insurers to update clinical review criteria, but then to rely solely on the clinical review criteria in making decisions, is a serious problem.

For example, we have an appeal now in which Aetna has relied on old clinical review criteria for a test called fecal calprotectin. The last time Aetna reviewed the criteria for this test, the test was not FDA approved. However, it was FDA approved in 2006, and there are reams of medical journal articles establishing that it is, in fact, the standard of care for patients with symptoms that could represent either inflammatory bowel disease or irritable bowel syndrome. We submitted a first-level appeal pointing out all of this and enclosing copies of the FDA approval and medical journal articles, and Aetna denied the appeal based on its clinical review criteria. We filed a second level appeal and got the same result. Our external appeal is pending. In a case like this, it should not take three (3) levels of appeal to get a mistake like this reversed. If Aetna updated its clinical review criteria, or even looked beyond its clinical review criteria to consider the material we submitted, we would have won our first level appeal.

Thus, we would urge the Committee to require insurers to evaluate their clinical review criteria annually.

4. Next, we have several concerns regarding the notice provisions set forth in Section 4(f).

   Here and in several other sections, the Bill provides that notice can be given electronically. We do not recall ever seeing a similar provision in any state or federal law or regulation. Many consumers still do not regularly use email. Insurers send email using secure programs that are very difficult to navigate. Email accounts may be shared among family members, or a consumer may

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[2] The NAIC Model Act includes, *inter alia*, as "medical or scientific evidence," published medical journal articles or articles accepted for publication. However, it is extremely burdensome for consumers to have to obtain the full-text of medical journal articles since only abstracts are available without charge on the internet; one either has to go to a medical library (if one is nearby) or pay quite a high price for copies of full text articles on the internet. We suggest that the Agencies consider accepting, as "medical or scientific evidence," abstracts published on PubMed.gov or other similarly-reliable internet-based services. Vermont allows the use of peer-reviewed abstracts presented at major medical association meetings. Vt. Admin. Code §§ 4-5-3:10.100(II)(6)(managed care organizations); 4-5-4.3(S)(6)(health insurers). However, even these would be difficult for consumers to obtain. Thus, peer-reviewed abstracts from reliable sources such as PubMed.gov should be accepted.

only have computer access in a public location like a library. All of these reasons militate against the use of electronic notices of adverse determinations.

Second, the section refers to a "denial code." We have never heard that phrase used by anybody in any context. What we believe is intended here is that, if a denial is in the form of an Explanation of Benefits (EOB), the insurer will place a code for the reason for the denial in the body of the EOB and then define that code below or on the back of the page. However, there is no code used for a prospective or concurrent denial since those denials come not in the form of an EOB, but in the form of a letter. Thus, to require a "denial code" in all cases does not make sense.

Third, the inclusion of diagnosis codes in the notice provision of the IFR has proven to be quite controversial. The more medical information is included in the denial, the greater the chance is that privacy will be breached. Denials are opened by other family members, or sometimes addressed to the primary insured rather than the patient. Further, consumers do not have access to diagnosis codes and will not know what the code means. Thus, while it is important to provide consumers with all the information they need in order to file an appeal, this concern must be balanced carefully against the right to medical privacy. We would suggest that the diagnosis code not be included in the denial itself. Rather, it would be available to any consumer that requests a copy of the insurer's file pursuant to Sections 4(f)(1)(F) & (G).

Fourth, Section 4(f)(1)(E) requires the insurer to provide a description of the insurer's internal grievance process. The Committee should require that this description include the address to which to send appeals. All too often, this simple but critical information is omitted, and we end up having to send appeals two and three times to different addresses that we are given over the telephone before the appeal reaches the right location. This is a simple matter to correct. Indeed, although we are not certain why this provision is not in the section of the Bill relating to notice of denials, Section 5(c) does require the insurer to provide the name, address and telephone number of the person or unit designated to coordinate the review for the insurer. We would simply urge that this information be required to be included in the notice of denial set forth in Section 4(f).

Finally – and most importantly – we believe that it is critical to say, explicitly, that it is not sufficient for an insurer to say that the reason for the denial is "not medically necessary," or even "this service is not covered under your plan," as insurers typically state. This is not a sufficient statement of the reason for a denial of coverage in that it fails to inform the consumer what he or she needs to do in order to mount an appeal.

We recommend that you consider some of the provisions of Maryland Insurance Code Ann. § 15-10A-02(f), which requires that the notice of adverse decision be in clear language and "reference[ ] the specific criteria and standards, including interpretive guidelines, on which the decision was based, and may not solely use generalized terms such as 'experimental procedure not covered,' 'cosmetic procedure not covered,' 'service included

under another procedure,' or 'not medically necessary.'" The elimination of the use of these sorts of generalized terms would greatly advance the ability of consumers to understand the reason for a denial, thereby better focusing their appeal.

Similarly, the requirements for the Massachusetts notice of adverse benefit determination are exemplary. In Massachusetts, the notice must include a substantive clinical justification that is consistent with generally accepted principles of professional medical practice, including but not limited to (1) identifying the specific information upon which the adverse determination was based; (2) discussing the insured's presenting symptoms or condition, diagnosis and treatment interventions and the specific reasons such medical evidence fails to meet the relevant medical review criteria; (3) specifying alternative treatment options covered by the carrier, if any; (4) referencing and including applicable clinical practice guidelines and review criteria; and (5) notifying the insured or the insured's representative of the proceedings for requesting external review. Mass. Regs. Code tit. 105 § 128.307(B). These requirements ensure that consumers will have a full appreciation of the basis for the adverse decision, enabling them to focus their appeals accordingly.

5. Although this pertains to notices, as well, we wish to separately comment on the requirement that notices be linguistically and culturally appropriate, including offering the notice in other languages. With respect to translation of written communications into other languages, our sense is that insurers that are balking at this are, at least to some extent, exaggerating the burdensomeness of this requirement. They would prefer to interpret notices orally rather than provide written notices translated into an enrollee's language. Oral interpreting seems to us to be far more expensive since expenses for interpreters would be incurred for each individual needing assistance. Having a set of templates prepared in each language that meets the regulation's thresholds, with only the patient-specific information having to be translated on an individualized basis, is likely more cost-effective. In addition, quality control is far easier when communications are in writing. The "paper-trail" is also critical to ensure appropriate notice. If oral communication is allowed, will a plan meet the requirement by leaving a message on an enrollee's answering machine? If the plan is unable to reach the enrollee within the time frames, are the timeframes waived and how does this impact the enrollee's rights? And what if an enrollee does not have a telephone or shares a telephone with multiple individuals with whom the enrollee would not want health information shared?

   Insurers and plans also complain that they do not know how to identify which insureds need translation into which languages. It would be simple enough to simply ask on enrollment forms whether translation of written communications is necessary, and in which languages. Most Medicaid and CHIP applications already do this and many have provided comments that the common application for the Exchanges should also collect this language. Further, most small businesses know if they have non-English speaking employees, and the native language of those employees, and they can furnish that information to the insurer.

While we agree that including "taglines" on notices in multiple languages is helpful when insurers do not have language specific information, this places a burden on insureds to affirmatively call the insurer to get additional information. Taglines should not be a compromise or option for plans but rather supplement the requirements to provide translated notices to ensure that insureds whose language needs are not noted are also informed of their rights.

Ensuring that people have the information they need means ensuring that they have access to that information in a form that they can comprehend. We simply do not agree that this requirement is unduly burdensome. Further, insurers that operate in California are already subject to similar requirements under state law. And any plan or insurer that participates in Medicaid, CHIP or Medicare should be translating notices for frequently encountered languages pursuant to Title VI of the Civil Rights Act of 1964 (see the HHS "LEP Guidance" at www.lep.gov). Weighed against the benefits of providing accessible information, the scale clearly tips in favor of translation.

Finally, please note that the Bill provides for linguistic and cultural appropriateness ONLY in section 4(f). Other notices to be provided – section 5(c), 5(i), and the other sections that require notices to be sent – also must include these requirements regarding linguistic and cultural appropriateness and, in particular, the availability of the notice in non-English languages.

6. Separately from our concerns about the drafting of Sections 5 and 6 set forth above, we have questions about Section 6 of the Bill.

   First, why or in what circumstance should a consumer be allowed to file an appeal from a decision that is not adverse to the consumer, as in Section 6(a)(1)(B)? And as to such appeals, sections 1 through 13 of the Bill do not apply pursuant to 6(a)(1)(B), so what procedures do apply to such appeals? We simply do not understand the intent behind this section. It should be clarified.

7. Next, it is our understanding that insurers and plans are opposed to a 24-hour deadline for deciding urgent care claims as set forth in Section 7(b)(1), preferring, instead, a 72-hour window. The preamble to the IFR explains the Departments believe that electronic communication has evolved to the extent that information can be conveyed, and decisions can be made, far more quickly than they could in 2000, when the original DOL regulation providing the 72-hour window was promulgated. There is an exception to the 24-hour requirement when the claimant has not provided all of the necessary information to the insurer or plan.

   These claims are, by definition, requests "for a health care service or course of treatment for which the time period for making a non-urgent care request determination (A) could seriously jeopardize the life or health of the covered person or the ability of the covered person to regain maximum function, or (B) in the opinion of a health care professional with knowledge of the covered person's medical condition, would subject the covered person to severe pain

that cannot be adequately managed without the health care service or treatment being requested." Section 1(38). Thus, they should be relatively rare, and in every case, time genuinely is of the essence.

8. Section 7(f)(1) and several other sections related to external appeals uses a "strict adherence" standard, which we think is the correct standard. Insurers and plans would prefer a "substantial" compliance standard to a "strict" compliance standard.

   This is not an overly punitive provision. The claim or appeal is not deemed approved; the deeming affects only the ability to pursue remedies outside of the plan. In light of the delays suffered by consumers, this standard is entirely appropriate.

   Time and time again, insurers lose, delay and even ignore internal appeals. If the consumer is represented by a third party and the third party submits a HIPAA release and authorization on its own letterhead rather than on a form buried on the insurer's website, insurers may either ignore the appeal entirely or fail and refuse to communicate with the consumer's representative. Over and over, appeals are lost or mistaken for a provider's appeal, so no notice of denial is sent to the consumer, and the opportunity to file a second-level or external appeal is greatly delayed. Consumers who failed to appreciate the likelihood that they would have to prove that they filed an appeal and, thus, did not send the appeal with a tracking mechanism (certified mail, delivery confirmation, etc.) have no recourse in the face of an insurer's assertion that it never received the consumer's appeal. At times, the insurer fails to provide an address – or a correct address – to which to send an appeal, requiring that it be sent over and over again until it finally is received. Indeed, these sorts of unjustifiable delays are one of the most vexing issues in filing insurance appeals. And insurers and plans alone have the ability to remedy these delays. Strict compliance is entirely within the insurer's or plan's control.

   The "substantial" compliance standard involves great ambiguity and subjectivity as to what is "substantial." Indeed, courts do not even agree on whether the question of whether a plan has substantially complied is a question or law or of fact. *Compare Ponsetti v. GE Pension Plan*, 614 F.3d 684 (7th Cir. 2010)(question of fact) *with Baptist Memorial Hospital – DeSoto, Inc. v. Crain Automotive, Inc.*, 392 Fed. Appx. 288 (5th Cir. 2010) (question of law). What constitutes substantial compliance is a question as to which the courts have not reached agreement; the courts articulate the standard slightly differently. *See, e.g., Simonia v. Glendale Nissan/Infinity Disability Plan*, 378 Fed. Appx. 725 (9th Cir. 2010) (substantial compliance exists in the absence of prejudice to the claimant); *Estate of Thompson v. Sun Life Assur. Co. of Canada*, 354 Fed. Appx. 183 (5th Cir. 2009) (substantial compliance exists if the violation was technical and the insured has a meaningful opportunity for review); *Larson v. Old Dominion Freight Line, Inc.*, 277 Fed. Appx. 318 (4th Cir. 2008) (substantial compliance exists when plan administrator provides a sufficiently clear understanding of the administrator's position so as to permit effective review). A strict compliance standard is far easier to enforce in that this same ambiguity and subjectivity is eliminated.

9. Section 9(a)(4) provides that external reviews shall be binding on the insurer. We believe that the Bill should also make clear that external reviews are *de novo*. The NAIC Model Act states that independent review organizations are not bound by any decision or conclusions reached during the health carrier's utilization review process. Section 8.D.2. This language should be included in Raised Bill 1158.

   In order to achieve true independence, external reviews must be *de novo*, and no deference should be shown to the plan administrator, as is set forth in the NAIC Model Act. An external reviewer should view the file anew, with fresh eyes and an unbiased viewpoint. The question is not whether there is any rationale pursuant to which the plan's decision can be upheld; it is whether the plan's decision is correct. Paying deference to what may well be an erroneous decision would only repeat the plan's error, if in fact one has been made. *De novo* review provides the best opportunity for accurate, unbiased outcomes.

10. Section 9(d)(4)(A) delegates to the insurer the determination of whether the request for external appeal is eligible for external appeal.[3] This task should be performed by the Commissioner, not the insurer. By providing that the insurer will complete this task, the Bill then must also provide that the Commissioner may reverse that decision, Section 9(d)(4)(D); but there is no requirement that notice of the ability to appeal to the Commissioner be provided, nor are any procedures in place for doing so. Of course, insurers have an incentive to look for reasons why an appeal might not be eligible for external appeal. To ensure independence in this aspect of the process, the Commissioner should make this determination.

11. The NAIC Model Act at section 8(c)(2) provides that, if preliminary review of an appeal indicates that it is incomplete, the issuer is required to notify the claimant and explain what information or materials are needed to make the request complete. This is a very important consumer protection. In 2003, the Maryland Insurance Administration indicated that 14% of medical necessity appeals were rejected because the consumer failed to provide necessary information. According to a 2005 New York State External Appeal Program annual report, 178 of 667 external appeals that were rejected – 27 percent – were rejected because the consumer failed to provide necessary information. Thus, we would urge the Committee to add a notice providing the consumer with an opportunity to cure in both internal and external appeals.

12. The consumer and/or his/her representative should be able to rely on the ground for coverage denial set forth in the notice of adverse decision. If an independent reviewer decides to uphold the denial for an entirely different reason than that on which the issuer/plan relied, the consumer and/or his/her representative should be given an opportunity to respond to this new rationale before a decision on the external appeal is issued.

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[3] There is a typographical error in Section 9(d)(4)(B)(ii). It states: "the health carrier shall notify the commission. . . ." The last word in that phrase should be commissioner.

We recently had a case in which proton beam radiotherapy for treatment of a tumor called acoustic neuroma was denied on the ground that proton beam radiotherapy was deemed experimental/investigational. We filed several appeals and, eventually, an external appeal. The independent reviewer found that proton beam radiotherapy is not experimental/investigational for the treatment of acoustic neuroma, but that the plan's definition of "medically necessary and appropriate" included a finding that the therapy in question was more effective than other covered therapies. The external reviewer found that other therapies were equally effective and ruled against us on that ground. At no time had the issue of how proton beam radiotherapy compared to other therapies been raised by the plan, and we never had an opportunity to respond to this point.

This was not a one-time occurrence. Recently, we filed an appeal from the denial of gastric electrical stimulation to a patient with idiopathic gastroparesis. There were four levels of appeal in all; the first three were denied based on the claim that gastric electrical stimulation is experimental/investigational. We updated our medical research and the medical records again before filing the final appeal, which consisted of approximately 1,000 pages of documents that overwhelmingly proved that gastric electrical stimulation is the standard of care for medically refractory idiopathic gastroparesis. The final decision we received rested on an entirely different rationale, i.e., that the patient's gastroparesis was caused by narcotic drug use due to chronic back pain, and was not idiopathic, thereby rendering the use off-label. We requested an opportunity to respond; in fact, our medical expert was prepared to state unequivocally that it is entirely unknown whether narcotic drug use can cause gastroparesis, and that, in this particular case, his best medical judgment is that the patient's past use of pain medication was not the cause of her gastroparesis. We received no response to this request. Within a month, this patient was on a feeding tube, in the hospital; her kidneys were shutting down; and her life hung in the balance.

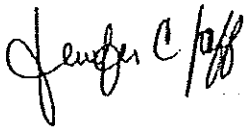
If an independent review organization is going to render a decision based on a rationale that never was raised before, the consumer must be given an opportunity to present his/her response to that rationale before a final determination is issued.

III. Conclusion

In our experience, the appeal process is integral to the goal of ensuring that consumers obtain the services covered by their policies, and that insurers make accurate, unbiased decisions. We hope that the foregoing analysis is helpful to the Committee in finalizing this important legislation. Of course, if we can be of any assistance, please do not hesitate to contact me.

Thank you.

Sincerely,



Jennifer C. Jaff*

Cc: Senator Joan V. Hartley, Vice Chair
Representative Susan M. Johnson, Vice Chair
Senator Kevin C. Kelly, Ranking Member
Representative Christopher D. Coutu, Ranking Member
Representative Mike Alberts
Representative David Aldarondo
Representative Emil Altobello
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Representative Robert Sanchez
Representative Linda Schofield
Representative Dave W. Yaccarino
Jeannette DeJesus, Special Advisor to the Governor on Healthcare Reform and Deputy Commissioner, Department of Public Health
Victoria Veltri, Acting Healthcare Advocate

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* Admitted to practice law in Connecticut, New York and the District of Columbia. Advocacy for Patients is a 501(c)(3) tax-exempt organization and does not charge patients for its services.