



February 19, 2019

The Honorable Seema Verma  
Administrator  
Centers for Medicare and Medicaid Services  
U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Re: Comments on *HHS Notice of Benefit and Payment Parameters for 2020* Proposed Rule,  
CMS-9926-P

Dear Administrator Verma:

We, the 87-undersigned patient and community organizations representing millions of patients and their families, are pleased to submit comments on the proposed rule, *Notice of Benefit and Payment Parameters for 2020*.

**I Am Essential** is a broad coalition dedicated to the advancement of quality, comprehensive, and affordable health care for patients, many of whom have serious and/or chronic health conditions. Our comments reflect the needs of these beneficiaries and their experiences in shopping for and utilizing the Qualified Health Plans (QHPs) over the past several years. The comments primarily focus on the need of patients to access a broad array of health benefits and services contained in the “essential health benefits” package with a particular focus on prescription medications, which are *truly essential* for our patients’ well-being.

**We are concerned that the intersection of strategies designed to contain health care costs is instead creating an undue cost burden for people with chronic health care conditions. In particular, we believe that the 2020 NBPP proposals such as prohibiting copay assistance when a generic equivalent exists, considering only a generic drug to be EHB, and the introduction of reference pricing place too much of the burden of containing prescription drug costs on patients, who have the least amount of power to effect systemic change. The confluence of more high-deductible plans with proposals to force consumers to bear the full burden of prescription drug costs puts people with serious, chronic health conditions at risk.**

We appreciate your consideration of our insights and concerns as we all work to improve the patient experience and health outcomes under the ACA, particularly for those with complex healthcare needs.

### **Proposed New Provision Not Counting Copay Assistance for Brand Drugs When a Generic Equivalent Exists**

CMS proposes to allow issuers to prohibit counting manufacturer copay assistance for a brand drug towards the deductible or cost-sharing limits when a generic drug is available, on the grounds that copay assistance may steer beneficiaries towards higher cost drugs. While we agree with the goal of reducing the cost of prescription drugs, we have significant concerns that this proposal puts the burden of high drug list prices on people with serious, chronic conditions who rely on prescription drugs – and on copay assistance to afford their medication. High deductibles and high cost-sharing for specialty medications expose patients to extraordinary out-of-pocket costs when they pick up their prescriptions at the pharmacy. People with complex medical conditions must have meaningful access to the best medication regimen for them, as prescribed by their doctor, even when those medications come with a cost. Many conditions impact each individual differently and similarly, many medications are not interchangeable. People can experience challenging or debilitating side effects from some generics of older generation medications, for instance, making a brand name medication the best option for them. CMS' proposal to allow issuers to not count this assistance for brand drugs when a generic drug is available can undermine meaningful access and exacerbate affordability concerns because of the high cost of many specialty generic drugs.

### **Shifting Costs to Consumers**

In 2019, the maximum out-of-pocket limit on health insurance plans for an individual is \$7,900 and \$15,800 for a family, with the average deductible for a silver-level qualified health plan being \$4,375. Moreover, specialty medications used to treat serious and chronic conditions, are often placed on formulary tiers associated with steep cost-sharing, sometimes upwards of 50 percent co-insurance. Research shows that when patient cost-sharing exceeds \$250, 69 percent of new prescriptions are not filled or are abandoned at the pharmacy.<sup>1</sup> Many insurance plans require people to exhaust their deductibles before contributing to the cost of prescription medications. Copay assistance programs are designed to ensure people are able to fill their prescriptions without having to come up with several thousand dollars at the pharmacy counter.

Some states have established separate cost-sharing limitations for prescription drugs, but those limitations generally do not take effect until after the patient has paid thousands of dollars up-front to meet the deductible. Delaware, Louisiana, Maryland, and Washington D.C. have placed co-pay caps on a 30-day supply of specialty-tier drugs at \$150, but after the deductible is met.<sup>2</sup> California also caps payments at \$250 but again, after the deductible has been met. Florida's

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<sup>1</sup> IQVIA. Patient Affordability Part Two: Implications for Patient Behavior & Therapy Consumption. <https://www.iqvia.com/locations/united-states/patient-affordability-part-two>.

<sup>2</sup>Kaminski Luduc, J. July 2016. Office of Legislature Research. <https://www.cga.ct.gov/2016/rpt/pdf/2016-R-0134.pdf>

Office of Insurance Regulation imposed safe harbor limits for HIV drugs, however many plans circumvent the cap by requiring the deductible to be met before the limitations are applied.<sup>3</sup>

The combination of high deductibles and high cost-sharing for prescription drugs is untenable for many and particularly those who have one or more health care conditions that require ongoing prescription medications. Drug Channels Institute recently analyzed Centers for Medicare and Medicaid Services' National Health Expenditure Accounts data, finding that total consumer out-of-pocket spending on prescription drugs was \$12.8 billion higher than consumer out-of-pocket spending on hospital care. However, total U.S. spending on hospital care was \$809 billion higher than overall spending on prescription drugs—demonstrating that consumers are bearing a disproportionate share of total prescription drug costs compared to other health care costs.<sup>4</sup> The CMS proposals regarding prescription assistance programs will worsen this imbalance, shifting even more of the burden onto the sickest people.

Manufacturer copay assistance programs help people access their medications by reducing the cost burden for the individual and helping them meet their deductible and maximum out-of-pocket spending limit.

### **Copay Assistance Used Primarily Where There Are No Generic Alternatives**

While some may claim that coupons are being used to incentivize brand-name drugs over generics, the fact is that 87 percent of the coupons are for drugs that have no generic equivalent. The 13 percent of branded drugs programs in which generic equivalent products are available accounted for only 0.05 percent of all prescriptions filled.<sup>5</sup> A study by IQVIA found that copay cards for products with a generic alternative are utilized 0.2% of the time a script is filled by any payer in the U.S.; 0.4% by commercial payers; and when isolating only brands with generic alternatives, 14.5% by commercial payers when a generic alternative is available.<sup>6</sup>

A study conducted by a team at USC Schaeffer found that of the top 200 highest-expenditure drugs with a co-pay coupon available, only 19 had a generic alternative. The authors found that there were few drugs that were close therapeutic substitutes and they “may not be suitable due to specific comorbidities, drug interactions, or other individual circumstances.”<sup>7</sup>

There are generally only brand drugs available for the treatment of many serious, chronic health conditions, such as HIV, epilepsy, cancer, and Lupus. They often are associated with high costs. Generic medications do not exist for many classes of drugs. However, when generic drugs do

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<sup>3</sup> Florida 2019 Safe Harbor Guidelines for HIV/AIDS Drugs <https://www.florir.com/sitedocuments/2019HIV-AIDSSafeHarborInstructions.docx>

<sup>4</sup> Fein, A. Drug Channels Institute. January 2019. Drug Channels News Roundup: Part D Plans Profits, Hospitals vs. Drugs, and BS in Healthcare

<sup>5</sup> IMS Institute for Healthcare Informatics. February 2014. “Patient Savings Program Use Analysis,”

<sup>6</sup> IQVIA. February 2018. “An Evaluation of Co-pay Card Utilization in Brands After Generic Competitor Launch.

<sup>7</sup> Van Nuys, K., Joyce, G., Ribero, R., Goldman, D.P. February 2018. A Perspective on Prescription Drug Copayment Coupons. Leonard D Schaeffer Center for Health Policy & Economics.

[http://healthpolicy.usc.edu/documents/2018.02\\_Prescription%20Copay%20Coupons%20White%20Paper\\_Final.pdf](http://healthpolicy.usc.edu/documents/2018.02_Prescription%20Copay%20Coupons%20White%20Paper_Final.pdf)

exist, the insurer, who is responsible for the formulary design, can easily select a generic drug and not include the brand drug under current ACA regulations.

### **Institution of “Copay Accumulator” Programs**

“Copay accumulators” are a practice that many insurance plans, employers, and pharmacy benefit managers are instituting that impedes access to medications. Such programs prevent manufacturer co-pay assistance contributions from counting towards a beneficiary’s deductible and maximum out-of-pocket spending limits. Currently, many issuers are adopting such policies without regard to the availability of a generic equivalent. This practice poses significant problems for patients, who may only learn about their issuer’s new policy at the pharmacy counter.

- **Lack of Transparency:** Insurance plans, PBMs and employers are implementing copay accumulator programs without providing sufficient consumer notice and burying the information deep within their benefit documents. For example, in Virginia, qualified health plans offered by CareFirst and Piedmont Community Health do not count the value of copay cards toward enrollee’s deductibles. These policies were buried in each plans’ Schedule of Benefits documents: on pages 134 and 135 of a 190-page document for CareFirst, and on page 46 of a 101-page document for Piedmont Community Healthcare.

The copay accumulator language can also be confusing, leaving the beneficiary wondering if the plan is implementing the policy. Florida Blue’s plans state, “We reserve the right not to apply manufacturer or provider cost share assistance program payments (e.g., manufacturer cost share assistance, manufacturer discount plans, and/or manufacturer coupons) to the Deductible or Out-of-Pocket maximums.” In the case of Health First, also participating in Florida’s individual marketplace, their plan documents did not include a mention of their policy on copay accumulators; however, based on communication with a plan representative, they could not guarantee that a copay card will count towards the member’s deductible.

This lack of clarity and transparency leaves consumers surprised when they discover mid-year that they have not exhausted their deductible despite having incurred significant prescription drug cost-sharing. At this point, they might be faced with an unexpected several thousand-dollar expenditure, which they will likely be unable to afford.

The CMS-issued Guidance for Individual Plan Summary of Benefits and Coverage Requirements edited in February 2016, explicitly states that if there is an out-of-pocket limit the issuer must list any major exceptions with the language, “even though you pay these expenses they don’t count toward the out-of-pocket limit.”<sup>8</sup> **Plans are clearly violating these important transparency requirements and we urge CMS to ensure plans are complying with them. Although we urge CMS to withdraw the proposed**

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<sup>8</sup> CMS Summary of Benefits and Coverage; Instruction Guide for Individual Health Insurance Coverage. February 2016. <https://www.cms.gov/CCIIO/Resources/Regulations-and-Guidance/Downloads/ccio-Individual-Instructions.PDF>

**change to § 156.130(h)(2), if CMS does adopt this proposal, it must also ensure that consumers are informed about it and the implications for their out-of-pocket costs.**

- **Issuers Gain Financially from Copay “Accumulator” Policies:** When issuers refuse to count manufacturer copay assistance towards deductibles and cost-sharing limits, they are essentially “double [or even triple] dipping,” by accepting the copay assistance dollars from the manufacturer, accepting rebates from the manufacturer (while charging the consumer based on list price), and still requiring the consumer to pay all cost sharing until the deductible and maximum out of pocket is reached.

In a case study of the total payments collected by a plan, modeled by the National Association of State and Territorial AIDS Directors, comparing two scenarios, one when copay assistance counts, and another when it does not under a copay accumulator program, the difference in the amount the plan collects is significant. Where an accumulator policy is not implemented—which permits the copay assistance to count towards the patient’s deductible and out-of-pocket costs—the plan would collect \$3,550 in payments from the beneficiary and the drug manufacturer. Under the scenario with the copay accumulator, the plan collects \$10,500.<sup>9</sup> This is a clear violation of the Affordable Care Act’s strict limits on out-of-pocket costs for consumers defined as any expenditure required by or on behalf of an enrollee with respect to essential health benefits; such term includes deductibles, coinsurance, copayments, or similar charges, but excludes premiums, balance billing amounts for non-network providers and spending for non-covered services 45 CFR 155.20.

### **Generics Are Not Always Affordable**

Copay assistance clearly does not steer patients to higher priced drugs when all the drugs used to treat a certain condition are brand name. **When there is truly a low-cost generic equivalent for a brand drug, we can understand the reasoning behind CMS’ proposal, however, in addition to generics not always being the best fit for an individual due to factors like side effects, not all generic drugs are low cost, and the use of generics do not always translate into low and affordable patient cost sharing. While in some instances a low-cost generic may exist for a brand drug, and it is placed on the generic tier, if the copay was all the patient had to pay, the proposed policy would be acceptable. But, at a time when insurance plan benefit design often includes high deductibles, it is also important to consider the beneficiary’s total costs. Since generic manufacturers also provide copay assistance for high cost generics, CMS’ proposal also would be possible in only those instances when total patient cost sharing for the generic is not greater than the brand drug.** People still will need copay assistance to afford and access their medications even if a generic exists.

While the overall list price for a generic equivalent for a brand name drugs may be lower than the brand drug, that price can still be extremely high. For example, the drug Imatinib, used to treatment cancer had a list price of around \$9,000 per month, but the generic at the time of its

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<sup>9</sup> NASTAD. Co-pay Accumulators: Considerations for HIV and Hepatitis. October 2018. <https://www.nastad.org/sites/default/files/Uploads/2018/copayaccumulatorfactsheet.pdf>

introduction was around \$8,000.<sup>10</sup> Glatiramer acetate is used to treat MS, and the brand has a list price of about \$7,500 per month, while its generic form is \$6,000 per month.<sup>11</sup> The brand drug of entecavir used for the treatment of hepatitis B was \$1,260 a month, but the generic today is over \$500.<sup>12</sup> **Therefore, for specialty generics, the cost of the drugs remains high and people still require copay assistance to access them.**

Recently, prices on generic drugs have been rising, steeply in some circumstances. New research has found that at least in one case, rising prices for generic drugs may be tied to more restrictive issuer policies related to cost for brand drugs. “Out-of-pocket drug costs are often tied to undiscounted list prices, and there appears to be a link between rising prices for [Multiple Sclerosis] drugs and more use of restrictive policies by Medicare drug plans,” according to researchers at Oregon Health and Science University.<sup>13</sup> In fact, the researchers found that at least in one case, “patients who are prescribed the only generic drug in one class -- glatiramer acetate - - will pay more out of pocket than patients using any brand-name drugs in the same class.”

### **Need for an Exceptions Process**

If CMS moves forward with some aspect of this proposal, we strongly suggest that there will be a clear, easily navigated, exceptions process for determining when a generic is “medically-appropriate,” and when it is not. The physician, who has specific knowledge of the individual’s health circumstances as well as the medical expertise, should be the final arbiter and be able to override an issuer decision while the consumer is at the pharmacy. It will be imperative that CMS ensure this is made known to providers, pharmacists, issuers, and patients.

### **Questions**

Additionally, we have a number of questions that we ask CMS to address:

- How will the agency define a “generic equivalent?”
- How will biosimilars be treated?
- What process will the agency use to ensure that people are able to have their brand name drug copay assistance count towards the deductible and cost-sharing limits when their physician attests that the brand is “medically appropriate” and the generic is not?
- What will the process be for determining whether a generic drug is “medically appropriate?”

The consumers represented by the I Am Essential Coalition have serious, complex medical conditions, and the answers to these questions will have significant impact on their ability to get the prescription drugs they need.

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<sup>10</sup> Cohen, J. September 2018. Forbes. The Curious Case of Gleevec Pricing.

<https://www.forbes.com/sites/joshuacohen/2018/09/12/the-curious-case-of-gleevec-pricing/#47a2e79854a3>

<sup>11</sup> Reinke, Thomas. June 2015. Managed Care Magazine. MS Drug Going Generic without Making Waves.

<https://www.managedcaremag.com/archives/2015/6/ms-drug-going-generic-without-making-waves>

<sup>12</sup> Hill, A., Gotham, D., Gooke, G., Bhagani, S., Andrieux-Meyer, I., Cohn, J., Fortunak., April 2015, Journal of Virus Eradication. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4946675/>

<sup>13</sup> Healthday.com. <https://consumer.healthday.com/senior-citizen-information-31/medicare-news-422/ms-drug-costs-skyrocket-after-medicare-rule-change-study-742382.html>

### **Implications for Copay Assistance for Brand Drugs When No Generic Exists**

As written, the proposal would prohibit the use of copay assistance for a brand drug when a generic exists. **We are assuming that CMS is asserting that copay assistance can be used, and should be counted toward deductibles and cost-sharing, for brand drugs that do not have a medically-appropriate generic.** This would therefore forbid copay accumulators for brand name drugs when there are no generic equivalents. **We welcome this interpretation and ask CMS to clearly state this policy clearly, enforce it, and to urge state Insurance Commissioners to also enforce this provision in their states.**

### **Proposed New Provision Allowing Issuers to Not Consider Brand Drugs Essential Health Benefits (EHB) if the Generic is Available and Medically Appropriate**

CMS proposes to allow issuers to only cover a generic when there is both a brand and generic available, and to then allow the brand drug to be considered not part of the EHB package. When a drug is not considered part of the EHB package, the person's cost-sharing would not count toward their deductible or the cost-sharing limits.

We have significant concerns that this proposal would undermine the definition of the EHB. Issuers already have wide latitude to determine which drugs are covered in their formularies, and to tier drugs such that cost-sharing amounts will steer people toward lower-cost and/or more effective drugs. Plans do not have to cover brand name drugs for which there is a generic equivalent. Additionally, all states have laws that provide for automatic substitution of a generic drug at the pharmacy when a provider prescribes a brand drug that has a generic alternative. Because there are already many incentives in the system to steer people towards generic drugs, we believe CMS is going after a problem that does not exist.

Not all patients respond the same to generic drugs as they do to the brand. While generic drugs are technically the same as brand drugs as far as active ingredients, they are not always identical. A generic may have different side effects or may interact differently with other drugs the patient may be taking. Therefore, it is imperative that the physician be the ultimate decider about whether a patient needs a particular brand drug, and in such cases, the patient should not be subject to cost penalties as a result of their brand drug use.

**We urge CMS to withdraw this proposal and to clarify that plans should ensure comprehensive access to medicine needed by people with chronic health care conditions, and ensure that people for whom a brand drug is the medically-appropriate option are not penalized by having their cost-sharing not counted toward their deductible and cost-sharing limits.**

### **Mid-Year Formulary Changes for Newly Approved Generics**

CMS proposes allowing issuers to make mid-year formulary changes when a generic equivalent prescription drug becomes available on the market. While we appreciate efforts to make generics available to enrollees as quickly as possible, we have serious concerns about the proposal to allow issuers to remove brand name drugs from the formulary within the plan year.

People with serious chronic conditions - like epilepsy, HIV, and mental health conditions - choose plans based on the coverage that is advertised. Treatment regimens for people with chronic conditions is not “one size fits all,” and many are carefully balanced to reduce side effects and drug interactions. Disrupting these regimes risks increasing side effects, adverse reactions and interactions, avoidable hospitalizations and emergency room visits and in some instances, irreversible damage or a public health concern. Consumers must have correct information when shopping for plans. In the proposed rule, CMS states that it “encourage[s] QHP issuers and Exchanges to undertake efforts to engage in consumer-friendly communication of their services to help consumers understand the value of the services they would potentially obtain,” and that such transparency will promote value and improve health outcomes. However, this proposal directly contradicts that effort. If finalized, this rule would allow an issuer to offer a product that is different than was advertised; because consumers are locked into the plan for a year, allowing plans to offer a product different than advertised will undermine consumers’ ability to make the best plan choices for their health. If CMS moves forward with this proposal, it should be limited to adding new drugs to the formulary; issuers should not be allowed to remove drugs until the new plan year.

People who do choose to switch to the generic will need time to schedule an appointment with their doctor, discuss side effects, and create a schedule for weaning off of a drug and beginning a new regimen. If CMS moves forward with allowing issuers to remove drugs from the formulary, it should also provide the maximum proposed notice period - 120 days - to allow enrollees to develop a new treatment plan.

### **Therapeutic Substitution and Reference Pricing**

We appreciate the ability to comment on two ideas that CMS is considering for future rulemaking: therapeutic substitution and reference pricing.

We have serious concerns about the consideration of therapeutic substitution. Therapeutic substitution may result in serious adverse outcomes for people with chronic conditions, who are frequently on multiple medications and have carefully calibrated treatments that are determined in coordination with their physicians. CMS acknowledges that for therapeutic substitution to become commonplace, “efficient systems that allow for seamless communication among prescribers, pharmacies, and insurance companies would need to be in place.” Such seamless communication does not currently exist. CMS may be considering allowing therapeutic substitution in order to “force” such systems. However, the people most likely to be hurt in that scenario are people with disabilities and chronic conditions, and any savings achieved are likely to be tempered by adverse drug interactions, avoidable admissions, and other poor outcomes.

We also have serious concerns about any proposal that seeks to reduce health costs by shifting more costs to consumers, especially those with chronic conditions who already face significant cost sharing. Introducing reference pricing to prescription drugs would only increase these costs and risk limiting patient access to drugs, thereby harming medication adherence. A study published in Health Affairs found that increasing medication adherence, even when controlling for confounding factors such as other indicators of a healthy lifestyle, reduced health care



utilization and costs.<sup>14</sup> Consumers - especially those with chronic conditions - already face significant cost sharing, including cost sharing that can impact medication adherence.

### **Silver Loading**

We appreciate CMS's decision to allow the practice known as "silver loading" to continue. We encourage CMS to continue to allow silver loading unless and until Congress takes action to appropriate cost-sharing reduction payments in a way that protects enrollees and promotes a stable health insurance market. Absent Congressional action, we believe this is the best way to protect low-income consumers and ensure that people are able to afford a health plan and the care they need.

### **Premium Adjustment Percentage**

As groups representing people with serious chronic conditions, we have concerns about the proposal to change the calculation of the premium adjustment percentage. As CMS notes in the proposed rule, the change in calculation would result in approximately 100,000 people losing Exchange coverage, with the majority of them becoming uninsured. This proposal will also result in higher premiums and higher cost sharing for Exchange enrollees. Such changes run contrary to the purpose of the Affordable Care Act and the Exchanges, and should not be finalized. **We urge CMS to withdraw this proposal.**

### **Auto Re-enrollment**

We strongly support HHS continuing auto re-enrollment for consumers who do not take action to select a new plan. Individuals who purchase their health insurance through the ACA have become accustomed to this practice which ensures continuous healthcare coverage, streamlines the health insurer process, and has also helped maintain a robust risk pool enrolled in the marketplace. Millions may lose coverage and risk interrupted care if auto re-enrollment were to be discontinued in the federally-facilitated marketplaces.

In response to HHS seeking comments on the procedures or policies that could help reduce eligibility errors we would recommend strengthening and modernizing data agreements with entities such as the Social Security Administration and Treasury and improve data matching reconciliation to ensure the most accurate information is available to determine an enrollee's eligibility and improve program integrity.

### **Maintaining and Enforcing Patient Protections**

As stated in the Proposed Rule, the Affordable Care Act contains many important patient protections that help in defining EHB and that all issuers must abide to when designing plan benefits. For example, plans must offer all ten categories of the EHB, the benefits must be equal in scope to a typical employer plan, there has to be an appropriate balance across all categories, and plan benefit design cannot discriminate based on an individual's age or disability. The EHBs must also consider the health needs of diverse segments of the population including women, children, persons with disabilities, and other groups.

In previous regulation, HHS has further defined EHB. For example, for prescription medications, every plan must cover at least the greater of one drug per class or the same number of drugs in

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<sup>14</sup> Health Affairs. <https://www.healthaffairs.org/doi/10.1377/hlthaff.2009.1087>

each category and class as the state's benchmark plan. Previous regulation also requires plans to be transparent in their coverage of benefits and costs, utilize Pharmacy and Therapeutic Committees, and consider newly approved medications and treatment guidelines. Plans must also not limit delivery of medications to only mail order. Additional regulations have been promulgated to implement Section 1557 of the ACA, which further defines discrimination in healthcare. HHS has also provided examples of discriminatory benefit design to include excessive patient cost-sharing, excessive utilization management techniques, such as prior authorizations, and placing every drug to treat a certain condition on the highest tier.

**As we wrote in a letter to HHS last year, continuation of these patient protections is critical so that qualified health plans meet the needs of patients, particularly those with serious and chronic conditions. We thank HHS for recognizing their importance by maintaining them and appreciate that in the *Letter to Issuers for 2020* other plan standards and expectations are maintained.**

**Patient protections are meaningless without proper enforcement.** Despite the law or regulation, some insurers still design plans that are discriminatory and limit patient access. Beneficiaries continue to encounter plans that lack meaningful formulary coverage for prescription medications, engage in adverse tiering, have high cost-sharing and burdensome utilization management requirements such as extensive and/or unwarranted prior authorization and step therapy requirements. Beneficiaries also still face midyear formulary changes, and can have their medications switched for non-medical reasons. Current regulations and guidelines must be enforced.

**We encourage HHS to fully enforce the patient protections contained in the law and in regulation, and ensure that if oversight and enforcement responsibilities are assumed by the states, they have the authority and resources necessary to fully address patients' protections, particularly non-discrimination in plan benefit design.**

Thank you very much for your consideration of our comments. Should you have any questions, please contact: Carl Schmid, Deputy Executive Director, The AIDS Institute, [cschmid@theaidsinstitute.org](mailto:cschmid@theaidsinstitute.org); Laura Weidner, Vice President, Government Relations and Advocacy, Epilepsy Foundation, [lweidner@efa.org](mailto:lweidner@efa.org); or Andrew Sperling, Director of Federal Legislative Advocacy, National Alliance on Mental Illness, [asperling@nami.org](mailto:asperling@nami.org).

Sincerely,

Action Wellness  
ADAP Advocacy Association (aaa+)  
AIDS Action Baltimore  
Aimed Alliance  
Allergy & Asthma Network  
American Association on Health and Disability  
American Autoimmune Related Diseases Association (AARDA )

American Behcet's Disease Association (ABDA)  
American Physical Therapy Association  
Autistic Self Advocacy Network  
Bronx Cares Family Medicine  
California Chronic Care Coalition  
California Hepatitis C Task Force,  
International Association of Hepatitis Task Forces

Cancer Support Community  
Caregiver Action Network  
Caregiver Voices United  
Chronic Disease Coalition  
Clinical Social Work Association  
Coalition on Positive Health Empowerment  
Community Access National Network  
(CANN)  
COPD Foundation  
Easterseals Massachusetts  
EPIC Long Island, South Shore Child  
Guidance Center  
Epilepsy Alliance North Carolina  
Epilepsy California  
Epilepsy Foundation  
Epilepsy Foundation of Alabama  
Epilepsy Foundation of Alaska  
Epilepsy Foundation of Arizona  
Epilepsy Foundation of Central & South  
Texas  
Epilepsy Foundation of Colorado  
Epilepsy Foundation of Delaware  
Epilepsy Foundation of Georgia  
Epilepsy Foundation of Greater Southern  
Illinois  
Epilepsy Foundation of Hawaii  
Epilepsy Foundation of Indiana  
Epilepsy Foundation Iowa  
Epilepsy Foundation of Kentuckiana  
Epilepsy Foundation of Long Island  
Epilepsy Foundation Maryland  
Epilepsy Foundation of Michigan  
Epilepsy Foundation of Minnesota  
Epilepsy Foundation of Mississippi  
Epilepsy Foundation of Missouri and  
Kansas  
Epilepsy Foundation of Nevada  
Epilepsy Foundation New England  
Epilepsy Foundation of Northeastern New  
York  
Epilepsy Foundation Ohio  
Epilepsy Foundation of Oklahoma  
Epilepsy Foundation Oregon  
cc: Randy Pate/CCIIO

Epilepsy Foundation of Utah  
Epilepsy Foundation of Vermont  
Epilepsy Foundation of Virginia  
Epilepsy Foundation Washington  
Epilepsy Information Service of Wake  
Forest University School of Medicine  
Global Healthy Living Foundation  
HealthHIV  
Hemophilia Federation of America  
HIV Dental Alliance  
International Foundation for Autoimmune &  
Autoinflammatory Arthritis (IFAA)  
International Pain Foundation  
International Pemphigus and Pemphigoid  
Foundation  
Lakeshore Foundation  
Let's Talk About Change  
Lupus and Allied Diseases Association, Inc.  
Lupus Foundation of America  
Lupus Research Alliance  
Mental Health America  
MLD Foundation  
Nashville CARES  
NASTAD  
National Alliance on Mental Illness  
National Association of Nutrition and Aging  
Services Programs (NANASP)  
National Coalition for LGBT Health  
National Consumers League  
National Council for Behavioral Health  
National Disability Rights Network  
National Hemophilia Foundation  
National Multiple Sclerosis Society  
National Patient Advocate Foundation  
New Jersey Association of Mental Health  
and Addiction Agencies, Inc.  
Prevent Blindness  
The AIDS Institute  
The Arc of the United States  
US Hereditary Angioedema Association  
US Pain Foundation  
Usher 1F Collaborative