American Kidney Fund®

October 6, 2016

The Honorable Andrew Slavitt
Acting Administrator
Centers for Medicare and Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

BY ELECTRONIC DELIVERY

RE: Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2018 [CMS-9934-P]

Dear Acting Administrator Slavitt:

Thank you for the opportunity to comment on the "Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2018" Proposed Rule (Proposed Rule).

The American Kidney Fund (AKF) is the nation's leading nonprofit organization working on behalf of the 31 million Americans with kidney disease. Our mission is to help people fight kidney disease and live healthier lives. We provide programs that educate the public and health professionals about kidney disease, help people at risk prevent kidney disease, and help low-income dialysis patients afford their healthcare expenses. AKF has been the financial safety net for our nation's dialysis patients since we were founded 45 years ago.

AKF is also a member of Kidney Care Partners (KCP). In addition to our comments below, we support the comments that KCP has submitted.

I. Guaranteed Renewability in the Individual Market and Medicare Eligibility

CMS Must Protect Patients' Right and Ability to Select the Health Coverage that Best Meets Their Needs

We request that as CMS finalizes the Proposed Rule, it ensures that end-stage renal disease (ESRD) patients will continue to have the right, and the practical ability, to select the health coverage that best meets their needs. CMS must protect patients against insurer actions that would steer patients away from a particular plan. These actions include paying secondary when an individual is merely eligible for Medicare, and refusing to accept a charitable premium payment made on behalf of an enrolled member, primarily because the member might have a high-cost condition like ESRD.

In the Proposed Rule, CMS notes that "Some issuers have a provision in their individual health insurance policies indicating that the coverage will pay secondary to Medicare not only for individuals who are currently covered by Medicare but also for those who could obtain Medicare coverage (such as those individuals who must pay for Part A coverage) but who are not currently covered." CMS asks for comment on the effects of such provisions on consumers.

We are deeply concerned about the effect of such provisions on the ESRD patient population. In developing such provisions, insurers are burdening ESRD patients with high out-of-pocket costs that will effectively force them onto Medicare or will leave them with devastating medical bills. Such provisions are a *de facto* way of allowing insurers to relieve themselves of covering high-cost ESRD patients.

For example, an AKF grant recipient from Waldorf, Maryland, is currently having his wages garnished by a healthcare provider because his employer health plan would only pay the Medicare rate, leaving the patient to pay out-of-pocket for any additional amounts charged by providers. This patient wanted to maintain family coverage through his employer, rather than go onto Medicare, since he is a single father supporting a young son. He is not able to pay the medical bills that have resulted from this insurer's action. He now faces a precarious legal and financial situation, and this challenge is placing him under enormous stress.

Just as this patient had a compelling reason to stay on his employer group health plan, the reasons ESRD patients might want to choose a Qualified Health Plan in the Marketplace (QHP) are numerous.

Since 1972, most ESRD patients have been able to participate in the Medicare program regardless of their age. The Medicare ESRD benefit has saved countless lives; without it, many ESRD patients would not be able to afford their treatment. However, the Medicare benefit structure also leaves patients with a significant 20 percent out-of-pocket cost burden that has no annual maximum. Only 27 states and the District of Columbia mandate that insurance carriers offer Medigap to ESRD patients under age 65, leaving patients in the other 23 states without access to this important supplemental insurance. For an ESRD patient with an average annual household income of $27,000, this 20% out of pocket expense is insurmountable. Thanks to Marketplace requirements in the ACA, when selecting a QHP, consumers can easily seek and compare information regarding monthly premiums and annual out-of-pocket maximums. This transparency allows patients the ability to plan financially; original Medicare alone does not offer that ability.

ESRD patients are also currently prohibited from joining Medicare Advantage plans, which can limit out-of-pocket costs. Medicare is also an individual health program; many ESRD patients are younger than the typical Medicare beneficiary and need family coverage.

Long-established Federal law recognizes the unique needs of individuals with ESRD and gives these individuals a choice between Medicare or private coverage. By enacting in 1981, and later extending, Medicare Secondary Payer (MSP), Congress has made clear that ESRD patients should not be forced onto Medicare. CMS has affirmed that being eligible for Medicare ESRD does not require enrollment in Medicare ESRD. The Internal Revenue Service has made clear that ESRD patients who have not enrolled in Medicare are eligible to enroll in a Marketplace plan with premium tax credit subsidy.[1] Department of Health and Human Services (HHS) guidance on Medicare and the Marketplace specifies that "Individuals with ESRD who do not have either Medicare Part A or Part B are eligible to enroll in individual market coverage because the Medicare anti-duplication statute does not apply; therefore, individual market guaranteed issue rights apply under the ACA."[2]

As demonstrated above, it has never been the Federal government's position that ESRD patients ***merely eligible*** for Medicare must choose Medicare over a QHP. There is no basis under the ACA, and it would be contrary to existing guidance, for CMS to promulgate regulations that will effectively force QHP enrollees with ESRD into Medicare as a matter of law. To be consistent with HHS guidance, ESRD patients who may be eligible for Medicare but not enrolled in Medicare, should have guaranteed renewability in a QHP.

Under the ACA, individual market QHP coverage cannot have limitations that do not exist in the group insurance market. The ACA mandates HHS to "ensure that the scope of essential health benefits [with respect to any QHP] is equal to the scope of benefits provided under a typical employer plan …."[3] Barring ESRD patients access to QHP coverage due to the ***availability*** of Medicare would relieve QHPs from their obligation to provide the chronic disease management coverage that is mandated as an EHB. There is no statutory or regulatory basis to force an ESRD patient out of a group insurance plan and into Medicare merely because of the patient's Medicare eligibility. Therefore, it would violate the plain language of the ACA to do so with respect to QHP issuers in the individual market.

Current regulations provide that a health insurance plan does not qualify as having EHB "if its benefit design, or the implementation of its benefit design, discriminates based on an individual's … present or predicted disability, degree of medical dependency … or other health conditions."[4] Allowing a QHP to pay costs as a secondary payer for ESRD patients merely because they are eligible for Medicare would undermine the QHP's ability to meet HHS' own standard for what constitutes EHB. Such a practice clearly

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[1] IRS, "Eligibility for Minimum Essential Coverage for Purposes of the Premium Tax Credit" Notice 2013-41.

[2] CMS, *Frequently Asked Questions Regarding Medicare and the Marketplace*, August 1, 2014, available at: *https://www.cms.gov/Medicare/Eligibility-and-Enrollment/Medicare-and-the-Marketplace/Downloads/Medicare-Marketplace_Master_FAQ_8-28-14_v2.pdf*.

[3] 42 U.S.C. § 18022(b)(2).

[4] 45 C.F.R. § 156.125.

constitutes the "implementation of [a] benefit design" that discriminates against individuals who have been diagnosed, or will be diagnosed, with ESRD and who seek coverage under a QHP pursuant to their right to do so. When ESRD patients sign up for a QHP, they expect to receive EHB as defined by HHS and the ACA. It would be improper to negate that coverage due to the availability of Medicare.

Forcing ESRD patients into Medicare would constitute a discriminatory plan design. Under the ACA, "a QHP issuer and its officials, employees, agents and representatives" must "not employ marketing practices or benefit designs that will have the effect of discouraging the enrollment of individuals with significant health needs in QHPs."[5] ESRD patients – who are frequently eligible for Medicare, but who are not legally required to choose Medicare over a QHP – are unlikely to enroll in a QHP if their coverage will be severely restricted because they are Medicare-eligible. Therefore, it would be improper for HHS to promulgate a regulation that would explicitly permit QHPs to adopt plan designs that discourage patients with ESRD (a "significant health need") from enrolling in their plans. Such a regulation would not only lead to discrimination against persons with the disability of ESRD, it would also lead to discrimination against racial and ethnic minorities, who develop kidney failure at higher rates than that of Caucasians.

We urge CMS to provide clear, unambiguous language in the final rule that aligns with longstanding federal law and regulations. Medicare coverage is often the best choice for ESRD patients, but not always. For example, a 35 year-old patient in Ohio with moderate chronic kidney disease due to Goodpasture's Syndrome was finally able to acquire health insurance for the first time in his life once the ACA was enacted. Previously, his pre-existing condition had excluded him from private insurance and he did not meet the income requirement for Medicaid. When his kidneys failed and he needed peritoneal dialysis to survive, his exchange plan remained in place. He has been able to afford the exchange plan because AKF pays his premiums. The patient has told us this assistance makes it possible for him to afford to eat. Because there is no Medigap coverage in Ohio for ESRD patients under 65, and because he doesn't meet the threshold for Ohio Medicaid, he would be forced to pay 20 percent out of pocket under Medicare if AKF could not help him with his QHP. He is already in crushing medical debt and cannot take on this extra expense.

CMS should make clear that ESRD patients who are eligible for Medicare may choose a QHP as primary payer. This clarification is necessary to protect patients from insurers inappropriately steering them away from QHPs and onto Medicare.

CMS Should Require QHP Carriers to Accept Charitable Premium Assistance on Behalf of Members

We ask the agency to recognize that many low-income ESRD patients do not have the practical ability to afford a QHP without charitable assistance. Nonprofits have historically served as the safety net for people with chronic conditions who cannot afford their health care. CMS must clarify the role of nonprofits in making third-party premium payments on behalf of enrolled members.

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[5] 45 C.F.R. § 156.225.

It is imperative that the Marketplace be strengthened so that it can function well for the millions of Americans who depend on this coverage. Strengthening the Marketplace involves making sure that it is an attractive market for insurers and an affordable option for consumers. HHS in recent months has made important strides toward this goal.

Insurers have very publicly stated that there are too many sick people in the risk pools, and not enough healthy people. In efforts to make the Marketplace more attractive for insurers, CMS must not take an action that would make it difficult or impossible for an entire class of disabled individuals (low-income ESRD patients) to have this type of insurance. Their departure from the Marketplace will not fix what ails the ACA; the number of ESRD patients involved is miniscule compared to overall Marketplace enrollment. But the inability of patients with ESRD to access this insurance will, indeed, cause individual patients great harm. CMS must promulgate regulations that protect these individuals' ability to rely on charitable aid.

AKF's Health Insurance Premium Program (HIPP) plays a critical role in ensuring that ESRD patients can benefit from the full range of insurance options to which they are entitled under the law. Without HIPP, a choice of coverage options would not be possible for far too many low-income ESRD patients who could not otherwise afford their premium payments, whether under Medicare, Medigap, COBRA, group coverage, or individual market plans. Individual ACA market coverage comprises a very small fraction of the assistance provided through HIPP—indeed, only 6,400 HIPP grant recipients, representing approximately 8 percent of our total HIPP grant recipients, and a tiny fraction (.05 percent) of the total 12.7 million individual market coverage enrollees, receive HIPP assistance to pay for individual market coverage.

One of the goals of the ACA was to open doors to such coverage for millions of Americans with life-threatening and expensive-to-treat conditions like ESRD. Indeed, the ACA acts expressly to guarantee dialysis patients the right to choose their health plan and—according to the plain text of the ACA—not to be subject to discriminatory practices.

Over the past two years, health insurance companies across the country have commenced an overt and forceful campaign to steer low-income ESRD patients off or away from their commercial plans—notwithstanding that such plans may be best for patients—by refusing or attempting to refuse patients' premium payments provided by AKF's HIPP program, which has existed for close to 20 years under HHS Office of Inspector General Advisory Opinion 97-1.

When insurers attempted to refuse charitable premium assistance on behalf of persons with HIV/AIDS in 2014, the Administration stepped in and issued an interim final rule mandating insurers to take premium payments from the Ryan White HIV/AIDS program. Today, we are asking that the Administration protect Americans with other chronic diseases in the same manner.

CMS' existing guidance on third-party payments has not been sufficient to prevent insurers from creating their own arbitrary rules to determine whether they will accept a payment from, or on behalf of, a policyholder. Insurance companies increasingly are picking and choosing the entities from which they will accept premium payments. Many insurers now explicitly state that they will only take premium payments from entities whom CMS has mandated as third-party payers (e.g., the Ryan White Program, Indian tribes and related organizations, and other government programs). Some insurers falsely state that CMS prohibits them from accepting third-party payments from AKF. Some insurers state that they will take third-party payments from policyholders' families but not from a charity, which means any ESRD patient not fortunate enough to have a financially supportive family cannot be insured. Some insurer decisions appear to be targeted specifically at removing ESRD patients from their books; one insurer in Idaho, for example, accepts premium support payments from a foundation on behalf of cancer patients, but not from AKF on behalf of ESRD patients. Some insurers are setting policies that give themselves complete discretion to refuse premium assistance from charitable organizations that the insurer, using its own set of criteria, deems to be "financially interested."

In addition to impeding patient choice and freezing out countless low-income individuals from their coverage, this conduct implicates violations of federal and state law prohibiting discrimination on the basis of disability, as well as on the basis of race and ethnicity—more than half of our HIPP grant recipients are people of color. The advocacy group Dialysis Patient Citizens filed a formal complaint with the HHS Office of Civil Rights on the discriminatory nature of this matter five months ago. As patients await the OCR response, adverse patient impact continues. Over the past two years, AKF has provided extensive information about these insurer practices to the Administration and we are hopeful that CMS will act expeditiously to affirm that insurance carriers must accept charitable premium payments from nonprofits that meet a set of defined criteria that protects both patients and the risk pool.

In 2016, insurers in 38 states refused to accept charitable assistance on behalf of individuals enrolled in their plans, limiting patient choice and skewing risk pools within those states. Since the 2017 NBPP went final earlier this year, three major carriers have returned AKF grant payments on behalf of close to 500 patients in 23 states, jeopardizing their health insurance coverage. Additionally, some checks have been returned directly to patients and their coverage has been dropped. Plan filings that we have seen for 2017 indicate this practice is spreading, with at least 50 insurance carriers across the country seeking to institute bans on charitable premium assistance.

Refusing these payments gives insurance companies complete discretion to turn ESRD patients away *en masse*. Apart from the basic unfairness of this practice, its real world impact will be devastating not only for the 6,400 AKF beneficiaries with individual market coverage, but innumerable others as well. Depending on how insurance companies determine whether a charity is "financially interested"—a question on which the insurers make themselves the sole arbiter—untold numbers of low-income people with numerous disabilities and/or chronic conditions could be summarily frozen out of their coverage. Applied to AKF, such a policy by these insurers completely ignores the fact that HIPP operates with the help of provider funding with written approval from the OIG, which expressly concluded that HIPP's design insulates AKF from precisely the conflicts on which these insurers purport to base their policies.

But the issue has now expanded beyond carriers refusing to accept a payment from a third party on behalf of a policyholder. Unbelievably, insurance companies are putting in place policies that restrict individuals' freedom to receive charitable assistance and use that money to pay their healthcare costs. Carriers including United Healthcare adopted this extremely restrictive policy in 2016, threatening to terminate the QHP coverage of any member who receives charitable assistance from entities not mandated as third party payers by the federal government. This carrier and its subsidiaries have sent letters to policyholders requiring them to sign declarations, under penalty of perjury, that they are not receiving charitable assistance or reimbursement to pay their premiums, and advising that their policy will be cancelled if they fail to sign and return the attestation document. (*Attachment A*.) AKF has recently become aware that some of its grant recipients have indeed had their policies terminated simply because AKF helped them. These dialysis patients are now on Medicaid. As one such individual recently commented to CMS:

> I lost my private insurance about three months ago. I'm on Medicaid now, but United Healthcare, which I had, gives you more options. It also came with dental care and Medicaid does not. United Healthcare kicked me off their insurance and said that a third party couldn't pay for me. No one forced or steered me to United, I picked it because it was the best plan for me. It's just unfortunate they got rid of me because I needed help with their bills… I have four kids. They are 15, 14, 11 and 7. I can't do the type of things I used to do with my kids, like teach them how to play sports and things like that because I fall a lot because my balance isn't any good. United Healthcare was going to help me out with it and send me to a neurologist but then they kicked me off my insurance. I have to try and see a Medicaid neurologist but it's been hard and takes a very long time to even get in to anyone. I'm also still trying to find a primary doctor now. I found one possibility but it is hard to see a doctor who will take Medicaid. You have to wait months to get an appointment. I didn't have that problem when I was with United Healthcare. I liked them. They were very good to me but then they kicked me off insurance. I'd be better off now with my old insurance because that's the insurance I chose and everything was working very well with them.

Filings for 2017 Marketplace plans signal the widespread expansion of egregious attempts by insurance carriers to dictate to low-income individuals how they may spend grant money they receive directly from a charity. Cigna, Healthnet, some Blues, and United Healthcare and its subsidiaries are seeking to prohibit people from using direct charitable assistance to pay their insurance premiums. This maneuver effectively blocks low-income ESRD patients from receiving grants from AKF (in the form of checks, money orders or prepaid debit cards) that historically we have sent to patients so that they may afford their chosen health coverage.

Some state insurance regulators have prohibited this practice on the part of insurers, but the states need the Federal government to step in and issue uniform regulations on the overall third-party payment issue and also specifically on this emerging issue of carriers attempting to dictate to individuals the sources from which they may receive personal funds. Many state regulators have stated to us that they are waiting from guidance from CMS. We believe it is a fundamental right of every American to receive charitable assistance and to use that assistance for important needs, including health coverage. Allowing insurance companies to require individuals to attest to the source of their personal income is antithetical to our nation’s fundamental principles of free speech and freedom of association. The government must not permit health insurance carriers to dictate to Americans what they may and may not do with charitable assistance that they have received from recognized 501(c)(3) charities.

We have previously proposed to CMS and to regulators in various states certain guardrails that we believe make it possible for legitimate charities to continue helping low-income patients pay for insurance, while also protecting against fraud and abuse:

- Bona fide 501(c)(3) charitable organization;
- Independent Board of Directors;
- Notification to or registration with a state agency such as the Department of Insurance;
- Procedures that include an application process, independent determination of financial need by the charity’s employees, and geographic diversity;
- Procedures that completely wall off provider donation information from the charity’s determinations of patient eligibility for grant assistance;
- Procedures that protect patient choice and prohibit any direction that the patient use only certain insurers or providers, and provide assistance for a full range of insurance products;
- Assistance to cover the entire policy year (not short-term assistance);
- Annual certification of a uniform set of income and asset criteria used to determine eligibility; and
- Compliance with all other applicable federal, state, and local laws and regulations.

These guardrails address charitable organizations’ independence from their donor sources—what we believe to be the central tenet of the ’97 Advisory Opinion and essential for the mission-focused and transparent operation of HIPP and any charitable organization that provides premium assistance for a particular disease.

We urge CMS to clarify in the 2018 NBPP that insurance carriers are required to accept third-party premium assistance from nonprofits that meet the above criteria; and further, to clarify that insurers may not require their enrolled members to attest to the source of their personal funds, and may not terminate an individual’s coverage simply because that person is receiving charitable assistance to help them afford health insurance.

AKF Supports the Proposed Risk Adjusters as a Positive Step toward Protecting ESRD Patients

As risk adjusters were meant to ensure that insurance carriers mitigate risk and lose any incentive to only treat the healthiest patients, AKF supports the steps that CMS is taking to recognize and protect ESRD patients’ access to insurance. Adjusting risk to account for the high-cost patients will better ensure that insurance plans are provided with additional funds for caring for higher cost patients. Persons with ESRD are expensive patients and insurers should have incentives to retain these patients and disincentives for releasing or rejecting them.

AKF supports the proposed RXC-HCC pair, which relates to ESRD phosphate binders. The provision would provide additional information beyond the actuarial valuation of these patients, and it would better ensure that the rate provided for risk adjustment better reflects the actual health care costs of the patient.

AKF also supports CMS's proposal to adjust the methodology to ensure that high cost enrollees are accounted for properly, which will ultimately lead to insurers losing the incentive to market and design plans that attract only healthy individuals. The correct risk adjusters will not only stabilize premiums, but will also lead to very ill patients having the access to QHPs as the ACA intended.

Conclusion
The Exchanges have offered health insurance to millions of Americans. Because of the work that the Administration has done, many Americans who would have lost everything due to their illness are no longer in that position. Now, the Administration must ensure that ESRD patients and other individuals with other chronic conditions have the same freedom of choice in insurance coverage as all other Americans. We appreciate the opportunity to comment on the 2018 NBPP and we look forward to continued dialogue with CMS on these important topics.

Sincerely,

LaVarne A. Burton

LaVarne A. Burton
President and CEO