

April 17, 2018

The Honorable Alex Azar  
Secretary  
U.S. Department of Health and Human Services  
200 Independence Avenue S.W.  
Washington, D.C. 20201

Dear Secretary Azar:

This week, you received a letter spearheaded by a group of financially interested parties—labor unions, health insurers, and employers—asking you to ensure their “employees and members [with kidney failure] receive the most appropriate [health] coverage to which they are entitled.” The letter has nothing to do with protecting patients. Full of misleading statements, omissions, half-truths and outright falsehoods, the letter has one true purpose: to limit the health coverage options of people with kidney failure by forcing them off private insurance and onto government health programs.

The truth is that the “most appropriate coverage” for a kidney patient is the coverage that they have chosen because it best meets their needs, whether that is public or private coverage. The federal government has given people with kidney failure a choice between private or public coverage for over three decades. But for those who have very low incomes, charitable assistance is what makes this choice possible. Charitable assistance is what gives a mother who has had to stop working because of being on dialysis the ability to keep her family insured through COBRA, instead of going onto Medicare, which doesn’t cover families. Charitable assistance is what prevents a dialysis patient on Medicare Part B from incurring financially crippling out-of-pocket costs. The financial dilemmas that kidney patients face are complex, and charitable assistance makes it possible for individuals to choose the health coverage that is the best for their own situation.

I am proud to be the President and CEO of the American Kidney Fund (AKF), the nation’s leading independent nonprofit organization working on behalf of the 30 million Americans with kidney disease. AKF is best known for its financial assistance programs that, for the past half-century, have made it possible for more than 1.5 million low-income kidney patients to afford healthcare so they can live the healthiest lives possible while being treated for life-threatening kidney failure. But AKF doesn’t just provide financial assistance. We fight the enormous public health threat of kidney disease on all fronts, providing prevention services to people at high risk for kidney disease; engaging kidney patients and caregivers with clear, understandable disease management health education; funding clinical research; working to increase the available supply of donor organs so that fewer people die waiting for a transplant; and advocating for policy changes at the state and federal levels to protect the health and rights of kidney patients.

Kidney failure, also known as end-stage renal disease (ESRD), is a devastating and life-changing disease that leaves patients unable to cleanse their blood of toxins and requires a treatment regimen of dialysis three times a week to stay alive. Those who are very fortunate receive a kidney transplant, but the supply of donor kidneys falls far short of the need; almost 100,000 people are waiting for a kidney transplant today. Most people on dialysis are no longer able to work.

AKF has been the safety net for low-income dialysis patients for nearly 50 years, and has assisted patients in paying their health insurance premiums for over 20 years under our federally approved Health Insurance Premium Program (HIPP), which launched in 1997. AKF has provided premium assistance for Medicare and Medigap, as well as private commercial, individual and group health care plans since then, operating under guardrails provided by the Office of the Inspector General (OIG) at the U.S. Department of Health and Human Services. This Advisory Opinion states that we will accept contributions from dialysis providers so that we can pay health insurance premiums for patients who meet our financial criteria. In 2017, we helped over 74,000 people pay for all forms of public and private health insurance.

The letter you have received from opponents of this program misleadingly states that “in agency actions, CMS has recognized steering by dialysis providers as a problem that could cause significant harm to individuals with ESRD and to the individual market as a whole.” The “agency action” this references is a CMS Interim Final Rule published in December 2016. What the letter fails to mention is that a U.S. District Court enjoined this rule on the merits. The court ruling was clear: CMS had not demonstrated any good cause to prohibit charitable premium assistance and, in fact, prohibiting such aid would harm kidney patients. In his opinion enjoining the IFR, U.S. District Court Judge Amos Mazzant wrote:

**“Not all ESRD patients qualify for Medicare, and Medicare does not cover family members. Further, many health care providers do not accept Medicare. Therefore, some ESRD patients and their families could lose access to their health care providers or even lose insurance coverage altogether.”**

Further, Judge Mazzant said that although CMS’s claim that the IFR was drafted to insure against mid-year disruptions in insurance coverage and continued eligibility for kidney transplants:

**“[The] defendants have not provided a single example of a patient denied a kidney transplant because of charitable assistance” and “the Rule would cause the very mid-year disruptions that it seeks to prevent.”**

The letter also falsely states that “dialysis providers are paying premiums through a financially interested third party—the American Kidney Fund—for ESRD patients to steer them away from Medicaid and Medicare and into commercial Exchange plans so that they can profit from the higher reimbursement rates paid by these issuers.” In contrast to this falsehood, below we share the facts about how AKF operates its program.

**First**, the financially interested parties who have sent you this letter would like you to believe that AKF only provides assistance for private insurance. In fact, we help people with all kinds of insurance, public and private, because we believe that low-income Americans with kidney failure deserve to choose the coverage that best meets their needs. Private insurance plans constitute a **minority** of our grant assistance. Over 60 percent of the grants we issue are to help patients pay their premiums for Medicare Part B and Medigap. Approximately 25 percent of our HIPP grants are for employer-provided health plans, including COBRA, a number that has held steady for nearly 10 years. In 2017, only 12 percent of our grant recipients enrolled in a commercial plan, including just 4 percent who were in ACA Exchange plans. (These grant totals add up to greater than 100 percent because some of our grant recipients receive AKF assistance with both primary and secondary coverage; for example, COBRA primary and Medicare secondary.)

**Second**, we are an independent nonprofit with a broad base of public support. Fully 61,000 donors—individuals, corporations and foundations—support our mission. The nation’s charity watchdog organizations have consistently recognized AKF as one of the nation’s most trusted, transparent and effective nonprofits. Charity Navigator, Guidestar, Consumer Reports and Charity Watch have evaluated AKF and have awarded us the highest possible ratings for many years running. Out of 9,000 charities evaluated by Charity Navigator, AKF is on the top 10 list of organizations with the most 4-star ratings. Consumer Reports has named AKF one of the two best health nonprofits in the country. We spend 97 cents of every donated dollar not on overhead but on programs that directly serve and educate patients and the public.

**Third**, AKF has been consistently transparent about how HIPP operates, including the fact that we receive contributions from dialysis companies for this program. Insurers have been accepting our payments since the program began under federal guidance 21 years ago. AKF maintains a firewall between voluntary contributions from dialysis companies to AKF, and the decisions AKF makes about how to distribute HIPP grants. Our donors do not, and cannot, influence individual patient grant decisions, and our program makes it possible for low-income dialysis patients to have the insurance coverage that is best for them. We provide grant assistance for the full plan year— not just episodic care such as when a patient has to be hospitalized—and our decision to award grants is based solely on strict criteria patients must meet to demonstrate their financial need.

The purpose of HIPP is to give low-income dialysis patients access to the coverage that best ensures that they will be able to meet their medical and financial needs, in keeping with our half-century-long mission of service to dialysis patients. Providers cannot earmark their donations to AKF to go to individual patients. In fact, 40 percent of dialysis providers with patients in the HIPP program do not make any contributions to AKF, and AKF has never turned away a dialysis patient who applies to us for assistance, provides full and accurate personal information, and qualifies financially.

The federal government has long recognized that someone who develops kidney failure should have the option to keep their employer coverage for a period of time before they must take primary coverage under Medicare Part B. Congress has explicitly given ESRD patients the choice to have private coverage since 1985 under the Medicare as Secondary Payer (MSP) program. MSP states that Medicare is secondary payer to group health plans for individuals eligible for, or entitled to Medicare benefits based on ESRD during a 30-month coordination period. And although most of the patients we assist do choose Medicare as their primary coverage, Medicare is not the best coverage for everyone. Many kidney failure patients are younger than the typical Medicare beneficiary and have families; they want to stay on employer or COBRA plans because Medicare doesn’t cover families. Further, in 23 states, ESRD patients under age 65 cannot get Medigap coverage, which means these patients, if they enroll in Medicare, are responsible for the 20 percent of costs that Medicare does not cover, with no out-of-pocket maximum. For a typical dialysis patient, this averages \$7,000 per year, which is a great deal of money if you are not able to work.

The letter you received also falsely claims that charitable premium assistance “is also potentially harmful to patient care and poses a barrier to both appropriate coordination of care for people with ESRD and timely access to a kidney transplant, particularly for low income patients.” In fact, ESRD patients who want to get a kidney transplant need primary and secondary insurance to become eligible for a transplant. AKF, by assisting people with their insurance, including Medigap, enables more ESRD patients to get on the transplant list and therefore increases the chances of the patient receiving a new kidney. Without our assistance, there would be fewer transplants, not more, and it is ridiculous to say otherwise. The federal

district court that enjoined the CMS IFR agreed—as mentioned above, Judge Mazzant noted that there was “not provided a single example of a patient denied a kidney transplant because of charitable assistance.” We hear from patients on a daily basis who are grateful to AKF precisely because our insurance premium assistance made it possible for them to have a transplant.

AKF pays for health insurance for the full plan year, which aligns with guidance HHS has issued on charitable premium assistance. For transplant patients, this assistance makes it possible to have the transplant surgery and get back on their feet and back to work after the transplant.

I would also like to address the letter’s fabricated claim that our charitable premium payments are often made through pre-paid debit cards “to avoid any transparency to health plans or employers and further attempt to game the system putting corporate profit before consumer needs and the efficiency of the health care system overall.” In reality, we have been very open with insurers about the fact that we often issue grants via prepaid debit cards to make it easier for patients to pay their insurance bills. Prepaid debit cards are the easiest way for patients without bank accounts to make these payments. As an example of our transparency, attached is the letter we sent to Blue Shield of California last year informing them about the debit cards. As we have publicly stated and informed insurers, we have also posted on our website [information](#) about how we both use debit cards and also provide direct checks to patients so that they may pay their insurance premiums in instances where health plans will not accept a direct payment from AKF.

Just as we vigorously defend patients against attempts by insurers to disenroll them, we adamantly defend patients from any attempts by healthcare providers to steer them into health coverage. That is why we have been strengthening our program in recent years, including instituting a provider code of conduct, a patient bill of rights, and increased communications directly to our grant recipients to ensure they fully understand their rights and responsibilities. All of these enhancements are discussed in detail [here](#).

We also believe that charitable assistance programs, in general, should operate under a set of uniform safeguards that protect patients’ rights while also protecting the insurance risk pools. We have been engaged in ongoing discussions with HHS, congressional leaders and state regulators about these safeguards, as we work together to develop a framework for how such programs should operate. We have also met with the insurance industry on these guardrails and we welcome further discussion. The guardrails can be found [here](#).

The letter you received this week from the group is part of a larger campaign by the Service Employees International Union (SEIU), which is engaged in a major effort to organize and unionize dialysis facilities in California and other states. As part of its strategy to target the dialysis industry, SEIU has teamed up with the health insurers who have long sought to remove kidney patients from their rolls. It is extremely concerning that real people who are living with kidney failure have been caught in the middle of this battle and are now being used as political pawns by these groups, who are working together in an indefensible attempt to discourage and outright reject their health coverage. In our opinion, that’s the motivation for what these groups are seeking to do both administratively and legislatively.

We would welcome the opportunity to discuss with you further. We at AKF are very proud of the work that we do on behalf of kidney patients. When a powerful coalition teams up to attack these patients, it is critical that our leaders in government understand the motivations behind those attacks.

Sincerely,



LaVarne Burton  
President and CEO