Teri Browne, PhD, MSW, NSW-C, LSW Response to Docket ID: CMS-2016-0145 September 22, 2016

Dear Centers for Medicare Medicaid Services:

Thank you for the opportunity to comment on the "Inappropriate Steering of Individuals Eligible for or Receiving Medicare and Medicaid Benefits to Individual Market Plans." I have worked in the nephrology community for 21 years, and am a certified nephrology social worker. I worked as a dialysis social worker for 13 years including at Gambro (now Davita) and Fresenius. I currently am an associate professor of social work and focus my research on psychosocial barriers to kidney disease outcomes, and kidney transplant disparities. I have spent decades serving and continuing to serve in local, national and international kidney organizations including several ESRD networks, kidney patient organizations, and was the national chairperson of the Council of Nephrology Social Workers. I am considered an international nephrology social work expert, and have presented across the country and around the world on kidney disease and nephrology social work issues (as well as published numerous book chapters and peer-reviewed articles on these topics).

Based on my personal experience as a dialysis social worker, and information I receive from dialysis and transplant patients and professionals from across the country, I know that there is indeed "Inappropriate Steering of Individuals Eligible for or Receiving Medicare and Medicaid Benefits to Individual Market Plans." The greatest focus of my work for Fresenius was to track and promote commercial insurance for our patients- they had a special form for this to track all patients with commercial insurance, and this was heavily promoted at a local and regional level as one of all social workers' primary tasks. The expectation was that all commercially insured patients keep their commercial insurance (using American Kidney Fund to pay the premiums), and not pursue Medicare or Medicaid if that meant the commercial insurance would not be the primary payor. Also, Fresenius prioritized efforts to procure commercial insurance for all patients without such insurance. The % of commercially insured patients was a metric used by all dialysis units as an important quality indicator, and constantly monitored.

In my capacity as a kidney disease scholar, I have the opportunities to speak with patients with ESRD, their care partners and nephrology professionals from across the country. I have heard from countless patients and professionals that for-profit dialysis companies continue to steer patients into commercial market insurance plans, despite their eligibility for Medicare and Medicaid. This is done by the companies billing departments, as well as by social workers directed by their company to do so. Tragically, this is done with no regard for the patients' existing coverage gaps (many times there are none) with Medicare and/or Medicaid, and no regard for the consequences of this efforts. I have heard from and about many patients who end up with large copayments, significantly reduced benefits, and drastically limited provider access and continuity of care because they are steered into commercial insurance plans despite their eligibility for Medicaid and/or Medicare.

For me, the most alarming phenomenon related to these practices is the barriers these practices create for patients to get kidney transplants and have successful transplant outcomes. What has happened is that patients are steered into these commercial insurance plans (or persuaded to keep their commercial insurance despite their eligibility for Medicare or Medicaid- this may be happening even more frequently than the "steering") with impossibly high premiums, which are paid by the American Kidney Fund. This allows the dialysis unit to charge commercial insurance rates for services. However, as soon as the patient receives a transplant, the patient cannot keep their insurance, because this "charity" premium funding from American Kidney Fund disappears (as the American Kidney Fund only helps those who receive dialysis because their funds for this program comes from dialysis companies). Patients are then stuck with this market plan, which is most definitely not in their best interest as a transplant patient as they cannot afford the premiums that American Kidney Fund once paid. In worst case scenarios, they also are stuck with penalties because they did not enroll in Medicare when they were eligible.

This results in dialysis patients not being eligible to get listed for a kidney transplant, or have serious consequences related to having no/inadequate insurance once they are transplanted. Horrifically, this impacts the country's most underserved patients the most (who cannot afford these commercial insurance premiums), further contributing to the kidney transplant disparity that already exists in this country and is a public health crisis. Kidney transplant is the best and most cost-effective treatment modality for ESRD- and these practices are seriously limiting access to this modality because patients are steered into insurance decisions (entering into market place plans or keeping commercial insurance when eligible for Medicare and/or Medicaid) that are only best for dialysis companies' profits, not patients' transplant pursuit. I have personally heard both Fresenius and Davita representatives talk about helping patients get commercial insurance as a priority (with American Kidney Fund paying the premiums), and have questioned them about the negative consequences for patients related to getting kidney transplants (to no avail). I have heard as recently as this week (and for many many years) horror stories from transplant social workers trying to work with dialysis patients who have insurance paid for by the American Kidney Fund, and how this is a serious barrier to getting patients transplants. This is absolutely unacceptable and unconscionable.

I know that the narrative from American Kidney Fund, the dialysis companies, and Dialysis Patient Citizens (which is **not an independent patient organization**- it was started by a for-profit dialysis company, the majority of its funding comes from Davita and Fresenius, and its CEO is not a patient) is that looking into this practice of steering is somehow taking away dialysis patients' "choices." One look at American Kidney Fund's Facebook page and other social media (<a href="https://www.facebook.com/AmericanKidneyFund/?fref=ts">https://www.facebook.com/AmericanKidneyFund/?fref=ts</a>) demonstrates how they are terrifying patients and making the narrative about how this request for information is taking away patient choice: "We believe all dialysis patients should be educated about their insurance options, and deserve to freely choose the insurance that best fits their personal needs." Dialysis Patient Citizens' newsletter stated: "Insurers are trying to kick ESRD patients off their plans in the health exchanges by refusing to accept charitable assistance for insurance premiums from

organizations like the American Kidney Fund. Tell CMS they shouldn't cave into insurers demands. Help us protect patient choice for insurance coverage by submitting your comments on the next page. You will be provided with talking points to formulate your comments, and they will be submitted to DPC."

As a social worker, I am fiercely protective of and an advocate for patient choice. However, currently, patients are not given the FULL information needed to actually make a choice- they are not informed about how their commercial insurance compares to Medicare or Medicaid as it relates to access to providers, continuity of care, copayments and deductibles for all providers (dialysis companies may waive these for patients, but certainly their other medical providers do not); how these plans will specifically impact their candidacy for transplant; exactly what happens if they do get a transplant but are dependent on the American Kidney Fund for premium assistance, etc. Patients also need to know how much more their dialysis companies can bill if they have commercial insurance (i.e. how their dialysis companies profit from this "choice"); how much their dialysis company contributes to the American Kidney Fund; how the vast majority of the funding for the American Kidney Fund and Dialysis Patient Citizens comes from for-profit dialysis companies (patients can make a choice to determine if that influences any information provided); how the CEO of the American Kidney Fund made over \$515,000/year in reportable and other compensation last year and received more than a \$40,000 raise in each of the last few years (patients can make a choice to determine if they think that the American Kidney Fund has no vested interest in this matter); and how the American Kidney Fund refused to help patients in dialysis units that did not pay into their fund (this has been the case in practice for years, this past year with all this scrutiny they do seem to be backing away from this). They also can be informed that the OIG opinion that allowed dialysis companies to make "donations" to the American Kidney Fund so that the American Kidney Fund's CEO can make more than \$500,000/year and they can pay patients' premiums, only mentioned Medicare and Medigap policies in their opinion, so it is unclear that any other assistance is even allowed.

If patients can get full information about all these things that are truly necessary to make insurance decisions, I am totally fine with patients choosing to pursue market insurance plans even if they are eligible for Medicaid and/or Medicare. Given that these decisions are very confusing and insurance plan benefits are constantly changing, perhaps requiring that patients be counseled by an independent insurance advocate that is not beholden to the forprofit dialysis company? (like the independent donor advocate we require for kidney transplants).

In regards to the specific questions for this request for information, the only people interacting with beneficiaries to determine proper enrollment may be dialysis company staff and insurance companies. We have no idea what questions are asked of the consumer to determine eligibility pathways, and this is the greatest problem. If this is only done by dialysis unit staff, they have a vested interest in promoting the dialysis unit's best interest, not the patient's best interest (and certainly not their interest outside of dialysis). Consumers are

connected to foundations or others who are in the position to provide premium assistance by their dialysis units! This is an extreme example of conflict of interest.

I strongly believe that if dialysis providers are allowed to continue to pay their patients' insurance premiums through donations to the American Kidney Fund, they must publically report premium assistance and cost-sharing waivers for individual market enrollees.

Thank you for soliciting comments on this very important issue.

Sincerely,

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