

Answers to questions from Roddy Boyd at SIRF:

- **What is the current (2016) average AKF HIPP payment? In 2015?**

The average HIPP grant is \$827, which covers a quarter (three months) of premiums. We are keeping pace with rising insurance premiums across all the types of health insurance that we help low-income patients to afford, including Medicare and Medigap (which represent over 60% of the patients we serve), commercial, COBRA, employer group health and commercial policies. Of the total people we assist, only 7% are in Marketplace Exchange plans.

For the patients we serve, that quarterly payment is lifesaving. Patients tell us that without our assistance, they would have to make impossible choices like whether to buy food or their prescription medications. Most dialysis patients are unable to work because they are too sick and treating kidney failure (and the many comorbidities that often accompany it) is more than a full-time job. Dialysis treatments alone consume the better part of three days of every week.

As you know, most of the funding for the HIPP program comes from voluntary contributions by dialysis providers. Like virtually every health-focused nonprofit, AKF receives substantial funding from the industry that treats the disease we focus on.

All contributions to the HIPP are placed in a single patient assistance pool, and grants are issued to patients on a first-come, first-served basis. Contributors are not guaranteed that patients in their clinics will receive grants, nor is contributing to the HIPP pool a requirement for receiving a grant. In fact, about half of the dialysis companies who have patients being assisted by HIPP do not contribute to AKF. No patient has ever been refused AKF assistance because the dialysis provider they use has not contributed to HIPP. The HIPP program operates under guidelines approved in an Advisory Opinion issued to AKF by the Inspector General of the U.S. Department of Health and Human Services.

- **With two LDO donors representing ~ 80% of your donations and a chief executive who worked at both of them, is the AKF aware of how central HIPP is to the revenue goals of DaVita and Fresenius?**

AKF is a nonprofit organization, founded 45 years ago to help patients pay for their health care as well as to educate the public and increase awareness about kidney disease and how to prevent kidney failure. Your questions regarding the financial and business operations of dialysis providers should be addressed to those entities.

Our chief executive, LaVarne Burton, has never worked for any dialysis provider. LaVarne spent many years on Capitol Hill and at HHS before coming to AKF. None of our employees has ever worked for a dialysis provider.

The current Chair of our Board of Trustees, Gail Wick, has been retired for some years and now volunteers her time to AKF as a way of continuing to support patients who have kidney failure and to whom she devoted her professional life as a nephrology nurse. During her career, she was one of the most respected nephrology nurses in the country. Gail is a dialysis pioneer—she started out 46 years ago as a nephrology nurse, in the days when dialysis was a new and relatively untested treatment that was available only to the wealthy. Her long and illustrious career did indeed include working for a broad cross-section of dialysis providers across the country and she is widely respected as an expert on clinical care and standards for dialysis patient care. Gail is a fiercely independent thinker whose commitment is to patients. She shares our unwavering focus on the wellbeing of dialysis patients and the quality of the care that

they receive. We are fortunate to have someone of her caliber volunteer to be our board chair.

- **Why won't AKF provide the equivalent financial support to someone receiving a kidney transplant as they do for those undergoing dialysis?**

With AKF helping them to stay insured, dialysis patients are able to access all the benefits of their health plan—dialysis treatment, routine medical visits, medications, and kidney transplant workup and transplantation. So many patients have told us that they would never have been able to get a transplant without AKF's support.

In fact, one of the greatest benefits of our program is that a patient with primary and secondary insurance is much more likely to be able to obtain a transplant than a patient who does not have comprehensive coverage. We are extremely proud of the fact that our program helps people to get transplants, and we continue assistance through the transplant process. Without HIPP, transplant would be financially out of reach for our grant recipients.

Insurance companies have maligned our mission in their attempt to make the point that our HIPP program isn't worthy of support. The fact that we are a dialysis-focused nonprofit and don't provide financial assistance to people who've received transplants is one of their main talking points. But we've always been very open about this fact. The people who work at AKF and volunteer at AKF understand that our mission, since the day we were founded in 1971, has been to help people on dialysis. A person on dialysis is going through a uniquely burdensome, life-threatening health challenge that is not only physically devastating, but financially devastating, as well.

The sad reality is that there are 100,000 people waiting for a kidney today, and not nearly enough donated organs. Only 17,000 kidney transplants were performed last year. The average wait time is 3-5 years. The vast majority of people who develop kidney failure will have to be on dialysis, and many ESRD patients will never qualify medically for a transplant.

From patients, we most often hear gratitude that our program is here to help them when they are going through a very unique, and challenging, time: dialysis treatment. Likewise, we frequently hear gratitude from those who've been fortunate enough to get transplants with our help. They are able to have transplants because we cover their health care. We want as many of our grant recipients as possible to have a transplant.

Our HIPP application materials and our patient brochure make clear to prospective HIPP grant applicants that we will pay premiums through the transplant and the quarter beyond. When individuals prepare for kidney transplant, they work with the transplant center on a financial plan that addresses, in detail, how they will maintain health coverage post-transplant. One important note is that Medicare will pay for immunosuppressive drugs for only three years post-transplant.

Any serious, life-threatening illness will expose an individual to financial devastation. AKF is the only nonprofit of its kind in any disease state—no other nonprofit provides a safety net as comprehensive as the one that we provide.

- **Is there anything in the AKF charter or other foundation documents prohibiting support for those in line to receive a kidney transplant or who have received one?**

As described above, AKF patient grants pay for insurance coverage that pays for services that a person needs to prepare them for transplant surgery and then pays for the transplant surgery itself.

- **Is the AKF aware of the allegations that LDO clinic employees have used the group to steer clinic patients away from lower cost medicare/medicaid coverage so they can obtain sharply higher reimbursements?**

We are adamantly opposed to the alleged steering—whether it’s steering by dialysis providers, or steering by insurance companies away from private insurance onto government plans.

One of the most critical things here is to preserve patient choice—of provider and of insurance coverage. We help patients exercise their options, even if they could not afford it on their own. Patients who receive HIPP assistance from AKF may change insurance plans and may change health care providers at any time—their grants are tied only to the patient’s financial need.

We believe it should *always* be the patients’ choice to select the insurance plans that best meet their health care needs. Over and over, the federal government has affirmed that persons who have kidney failure should choose from the insurance options that best meet their health and financial needs. No one—whether a provider or insurance plan—should infringe upon this patient right.

We continuously look at how we can improve the HIPP program to best meet patient needs. Just last week, we announced additional steps that we will take to increase patient awareness of their right to choose their insurance coverage and to ensure that they are well informed to make these decisions. We also are instituting program requirements to ensure patients are indeed the ones who are selecting their insurance plans. We recently met with CMS and described to them additional steps that we will take to protect patient choice and we expressed our commitment to work with CMS to protect patient choice.

We are also aware that insurance plans around the country have been instituting policies and practices that have the effect of inappropriately steering patients out of private coverage and into government programs even when such public programs are not in the patient’s best interest. In fact, for several years we have been reporting our concerns to CMS. Some major insurers are going so far as to force their members with ESRD to sign attestations, under penalty of perjury, that they are paying their insurance bills with their own money and are not being helped by a charitable nonprofit. We can provide these documents to you.

We are taking steps to help ensure that inappropriate steering does not occur using our HIPP program—even one person steered into a plan that may not be best for them is too many. Specifically with regard to ACA plans, one of the enhancements we announced last week will require that AKF be provided justifications as to why a patient is selecting such an ACA plan instead of Medicare or Medicaid and show that they have reviewed all their options before turning to AKF for premium assistance.

In addition to the justification of ACA coverage, we are increasing our communications to patients and emphasizing that patients know they can always come to AKF with questions or concerns. Our patient guidebook, written in plain language, contains important information about the program and clarifies patients’ freedom to choose their own providers and the insurance plan(s) that best meet their needs. We are developing new educational materials to provide patients with objective information about their insurance options. We also announced:

- **A Provider Code of Conduct** that each referring dialysis provider must sign. The Code of Conduct requires dialysis providers to keep the best interests of the patient in mind when referring patients to AKF for assistance, and requires providers to give patients comprehensive, accurate, and impartial information enabling them to make informed decisions about their health insurance

coverage. Such comprehensive information will include financial and coverage-related implications associated with the choice of a particular coverage option.

- A **Patient Bill of Rights** that outlines for patients their rights and responsibilities regarding their receipt of HIPP grant assistance. This document explains patients' freedom to independently choose their health care coverage and providers, to make changes in provider or coverage, to register online to track their AKF grant status, and to report to AKF any concerns about the program, including whether there are concerns that patients' rights under HIPP have been violated.
- **Why not cut out the "middleman," i.e. clinics, entirely? Simply have patients call up the AKF and apply for HIPP themselves. Clinics could have prominent signage and/or brochures at hand for patients? If they're interested in AKFs HIPP the patients make the first move.**

The majority of patients we help with our HIPP program—more than 60 percent—are Medicare and Medigap patients. Because dialysis providers are required by Medicare to employ social workers, they institutionally and logistically are well positioned to help patients understand the complexities of Medicare enrollment, inform patients of the tradeoffs between Medicare/Medicaid and individual market coverage, and to help patients navigate the web of other coverage options, including Medigap, COBRA, employer group health plans and commercial plans both on and off the exchanges. The social workers provide resource referral for a variety of patient needs with AKF being one of those resources.

Patients are aware of our program and can complete our financial eligibility worksheet and bring that to the social worker who can submit the application on behalf of the patient. One of the critical roles the social worker provides is verification the patient is indeed a dialysis patient and secondly, that the information presented on the application is accurate based upon their knowledge of the patients' situation.

We do make it possible for patients to register in our grants management system so they may view the status of their grant application and their grant. We are encouraging more patients and their caregivers to take advantage of this resource.