# Memo: Coverage of outpatient dialysis services for undocumented immigrants with End-Stage Renal Disease in the State of Oregon.

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#### Goal:

To establish a justification for the outpatient treatment of end-stage renal disease, including dialysis and its related treatments, for undocumented immigrants living in the State of Oregon. Currently, undocumented immigrants are only eligible for emergency-only hemodialysis as traditionally dictated under federal law. This system, historically referred to as "compassionate dialysis," is unfair, costly, and unjust. Emergency-only hemodialysis places a patient's life at risk, results in more hospital admissions, and engenders greater spending from preventable complications. Furthermore, patients miss wages from lost labor and the community loses a productive person. The state of Oregon should provide the standard of care for dialysis to all patients within its borders. As the Renal Physicians Association notes, the "financial burden of uncompensated care provided to both citizens and non-citizens is both a federal and state responsibility." Notably, California and Washington, as well as several other states, have developed policies to provide the same standard of care for all patients with end-stage renal disease.

### **Abbreviations:**

EOHD – emergency only hemodialysis

EMTAL – Emergency Medical Treatment and Labor Act

ESRD – end-state-renal disease

SHD – standard hemodialysis

UIs – undocumented immigrants

US – United States

### **Literature Review:**

## <u>Undocumented Immigrant Prevalence and Impact</u>

- There were approximately 12.1 million UIs in the US in 2014.<sup>2</sup> Approximately 6,500 UIs have ESRD.<sup>3</sup> They are primarily Hispanic and younger than the overall US population with ESRD.<sup>4</sup> Notably, Hispanics with kidney disease have higher rate of progression to kidney failure (perhaps by 1/3).<sup>5</sup>
- In Oregon, there are approximately 130,000 UIs, representing 3.2% of the state population, and 32% of immigrants.
  - o UIs represent approximately 4.8% of the state workforce (without significant change since 2009).<sup>6,7</sup>
  - The Portland-Vancouver-Hillsboro metro area contains approximately 90,000 UIs. This represents 28% of the immigrant population and 3.7% of the overall population. This is the 22<sup>nd</sup> most populous metro area for UIs in the US.<sup>8</sup>

- The number of UIs with ESRD in CA has not grown despite polices covering outpatient dialysis.<sup>3</sup>
- UIs have added \$300 billion to the Social Security Trust Fund.<sup>3</sup>
- UIs paid \$80 million in state and local taxes within Oregon in 2014.<sup>7</sup>

#### **Emergency-Only Hemodialysis Quality and Costs**

- In a review of UIs with ESRD on EOHD in Denver, Colorado, from 2005-2017, the median age of death was 57 after only 16 months on dialysis (median duration on dialysis). This is reduced relative to the remainder of patients on dialysis in the US.
  - o Over half of patients died from cardiac arrests or arrhythmias, many of which are preventable with appropriate dialysis.
- A retrospective cohort study comparing EOHD (in Denver and Houston) to SHD (in San Francisco) from 2007-2014 demonstrated a 14x higher 5-year mortality rate among EOHD patients with 9x more hospital days. 10
  - o The SHD patients had safer and more effective hemodialysis vascular accesses, better nutrition, and better anemia measurements.
  - The increased mortality rate in patients with EOHD is similar in tone to the increased mortality seen in patients who miss treatments on SHD or on the dialysis "weekend" with two days in between treatments.
- A cost review from Houston, Texas revealed that EOHD was 3.7x more expensive than SHD (\$285,000 vs. \$77,000).<sup>11</sup>
  - This cost difference was primarily by increased emergency and hospital care as well as the requirement for more procedures for EOHD patients.
- The substandard care provided by EOHD directly affects a patient's quality of life.
  - o A 2017 study on the "illness experience" of UIs with EOHD demonstrated the stress of repeat episodes of life-threatening experiences due to the ineffective removal of toxic wastes and excess water.<sup>12</sup>
  - $\circ$  Symptom burden (e.g. nausea and shortness of breath) is higher with EOHD compared to SHD and quality of life is reduced.  $^{11,13}$
  - Patients on EOHD work less. According to one study employment reduced from over 90% prior to starting dialysis to 14% while on EOHD.<sup>14</sup>
  - Patients are generally not eligible for kidney transplants despite being healthier overall compared to the ESRD population and often having potential living donors.<sup>15</sup>
- Healthcare providers experience stress due to the substandard care of EOHD. A qualitative study of providers in CO and TX demonstrated that EOHD contributes to provider burnout and moral distress.<sup>16</sup>
  - This included concerns about witnessing suffering from unnecessary morbidity and mortality, conflicting financial incentives in medicine, the different standards of care between patients, and wasted healthcare resources.

### Existing Coverage and Policy History for Standard and Emergency-Only Dialysis

- Nearly all US citizens and 5-year permanent residents are eligible for SHD via the 1972 ESRD Amendments to the Social Security Act (Public Law 92-603).
- The 1986 Consolidated Omnibus Budget Reconciliation Act prohibits federal Medicaid payments to be used for care of undocumented immigrants except for emergency care as part of EMTALA. EMTALA requires the provision of "emergency" care for all individuals, regardless of their citizenship.

- The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 further explicitly denied all state and local public health benefits to UIs while forcing states to pass specific laws related to their own state coverage<sup>5</sup>
- However, "these restrictions left states to determine independently what public benefits would be offered
  to undocumented immigrants and restricted federal funds to the treatment of an emergency medical
  condition" and "this broad definition [of emergency] allows individual states some flexibility to determine
  what emergency medical conditions will be covered with Medicaid funds."<sup>5</sup>
- The Affordable Care Act does not cover UIs.
- In Oregon, SHD is not covered for UIs. Instead Citizen/Alien-Waved Emergency Medical (CAWEM) statues cover emergency care that does not include SHD as well as labor and delivery. Dialysis is listed among the several exclusions to coverage. <sup>17(p59-60)</sup>
- Several states have been able to cover SHD for UIs. As above, the flexibility of how to cover UIs for SHD stems from the fact that "CMS defers to states to identify which conditions qualify as emergency medical conditions." 5,10
  - o Court cases have challenged interpretations of "emergency only" medical services for Medicaid<sup>3</sup>
  - States offering outpatient SHD coverage for UIs through emergency Medicaid include AZ, CA, DE, DC, FL, IL, MA, MN, NY, NC, VA, WA.<sup>18</sup> Benefits vary from individual dialysis treatments alone to including dialysis related medications and/or procedures.
  - o For example, for over a decade Washington state has covered SHD as an emergency service along with other basic medical care for UIs including dialysis related surgeries. <sup>19</sup> Colorado began covering standard hemodialysis and associated care in February of 2019.
  - o Notably, large dialysis organizations have not objected to providing SHD to UIs when funding exists.

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