

## **A STRING OF PEARLS**

REFLECTIONS ON MEDICINE AND SOCIETY

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### **A CONFLUENCE OF INFLUENCE IN KIDNEY CARE: How did we get here?**

Do you remember the Ice Bucket Challenge of 2014? In a literal global outpouring, people assembled virtually to raise awareness and money for amyotrophic lateral sclerosis (ALS). Pat Quinn and Pete Frates, two people with ALS, started the online campaign raising over \$220 million dollars. A confluence of the right people, right time, and right message created a pivotal, pinnacle moment of influence for ALS.

October 2022 will mark the 50<sup>th</sup> anniversary of a similar moment for End Stage Kidney Disease (ESKD). On October 30, 1972, President Richard Nixon signed into law the Social Security Amendments of 1972, Public Law (PL) 92-603, that included section 299I. This brief section of PL 92-603 extended Medicare health insurance coverage to people younger than the Medicare qualifying age of 65 years who were diagnosed with ESKD and required hemodialysis or renal transplantation to live.

Why was this section added? Who championed Medicare funding of ESKD? What makes this a pivotal moment for kidney disease care?

In Seattle, WA on March 9, 1961, Clyde Shields became the first chronic hemodialysis patient when a Scribner shunt was surgically placed in his arm enabling repeated hemodialysis treatments over a long period of time. Clyde lived for 11 years on dialysis. Before March 9, 1961, ESKD mortality was 100%...everyone with ESKD died...EVERYONE! Chronic hemodialysis had never been done, so Clyde Shields and the patients who followed were considered research subjects for this treatment. Between 1963 and 1969 the Veteran's Administration (VA), the National Institutes of Health (NIH), and the Public Health Service provided grants and funding for programs to advance dialysis knowledge with programs including the "artificial kidney/chronic uremia program" and the "Kidney Disease Control Program (KDCP)".

As early as 1962 public media took note of hemodialysis as a life-saving treatment. In November 1962 Shana Alexander authored a Life Magazine article with the story of John Myers, a 37 year old man dramatically saved by being chosen to receive chronic dialysis, as the centerpiece of an overview of dialysis. John Myers was chosen by "The Admissions and Policies Committee of the Seattle Artificial Kidney Center at Swedish Hospital" aka the "Life and Death Committee" to be one of a few patients in the dialysis "trial" in Seattle. Patients with ESKD were pre-screened by physicians to eliminate children, anyone older than 45 years, and anyone with any diseases other than kidney disease. The admissions committee further considered personal data such as the number of dependents, income/net worth, educational background, and occupation/rehabilitation potential to select individuals for treatment. Dialysis was perceived as a difficult treatment that was emotionally and physically demanding. In 1962 as 5 people dialyzed in Seattle, an estimated 100,000 Americans died from ESKD. This treatment was a scarce, expensive, experimental resource costing \$15,000 per patient per year (approximately \$140,000 in 2022 dollars). As one of the admissions committee members said, "The situation as I see it, is life and death, complicated by limitations of money".

The Life Magazine article and a concurrent NBC documentary, "Who Shall Live", along with physician and patient experience with dialysis led to growing pressure on state and federal lawmakers to consider more funding for ESKD treatment. In 1966 The U.S. Bureau of the Budget sponsored the "Committee on Chronic Kidney Disease", chaired by a nationally respected nephrologist, Carl W. Gottschalk. The "Gottschalk Report" distributed in 1967 was not widely seen by U.S. Congressional members and staff, but it significantly influenced the medical community. The Gottschalk committee reviewed all dialysis data and concluded that hemodialysis was not a research treatment any longer, but was an effective, "established therapy" for ESKD.

By the late 1960s the lay press was active in highlighting the life and death decisions dialysis created and the nephrology community had enough data and experience to know that dialysis was a potential life-saving treatment for many people. Patients, families, and nephrologists were lobbying state and federal politicians to consider funding to increase access to dialysis care. They were also creating advocacy groups like the National Kidney Foundation (NKF) and the National Association of Patients on Hemodialysis (NAPH). Influencers of the time were eminent nephrologists like George Schreiner, Willem Kolff, John Merrill, and Belding Scribner who led the nephrology community and had access to influential legislators. The medical influencer message was amplified by the growing number of surviving dialysis patients and their families who became vocal, passionate advocates for dialysis funding. By the early 1970s there were enough people alive on dialysis to organize and actively advocate for improving access to care.

Access to dialysis care would require money and funding through legislation by congress. Medicare was enacted in 1965 and by 1970 a bipartisan effort was underway to evolve aspects of Medicare, especially regarding provisions for people with disabilities. In 1970 congress attempted but failed to complete Medicare legislation, so some high-ranking legislators including Wilbur Mills (D-Ark), chair of the House Ways and Means Committee, and Russell B. Long (D-LA), Chair of the Senate Finance Committee, were committed to passing legislation in 1972, an election year.

The 1972 Medicare legislation was 1,300 pages long and contained provisions for extending Medicare to individuals with disabilities, but until the last minute had no provisions for people with ESKD. Testimony regarding lifesaving dialysis was heard in open House Ways and Means committee hearings in November 1971 and included a dramatic short dialysis treatment on the committee room floor by Shep Glazer, a New York dialysis patient and leader of the NAHP. During 1971 and early 1972 George Schreiner and an Arkansas nephrologist, William Flanigan, testified in congressional national health insurance hearings. The NKF had a prevalent lobbying presence and, notably, former First Lady Mamie Eisenhower who was a member of the NKF board, successfully lobbied to have "kidney failure treatment" on the 1972 Republican Party election platform.

In December 1971 Wilbur Mills was swayed by the testimony and lobbying efforts of the kidney community and offered a personal bill, H.R. 12043, with this statement:

*"...to assure that any individual who suffers from chronic renal disease will have available to him the necessary life-saving care and treatment for such disease and will not be denied such treatment because of his inability to pay for it."*

This bill was not included in the final House version of H.R. 1 and was not part of the senate discussion of the Medicare bill until Saturday morning, September 30, 1972, when Indiana Senator Vance Hartke (D-Ind) provided this statement as an amendment to the bill:

*“In what must be the most tragic irony of the twentieth century, people are dying because they cannot get access to proper medical care. . . . More than 8,000 Americans will die this year from kidney disease who could have been saved if they had been able to afford an artificial kidney machine or transplantation. These will be needless deaths—deaths which should shock our conscience and shame our sensibilities. . . . We have the opportunity now to begin a national program of kidney disease treatment assistance administered through the Social Security Administration, and I propose that we take that opportunity so that more lives are not lost needlessly.”*

The Hartke amendment to provide coverage for ESKD treatment under Medicare passed in the senate with 52 votes in favor, 3 dissents and 45 senators absent and not voting.

In a comprehensive article on the Social Security Act amendments that led to Medicare coverage of ESKD treatment, Richard Rettig offers some insight into why it passed congress at that particular time in 1972 and here is a summary of some of his conclusions:

- Congress was committed to legislation to expand Medicare especially to cover people with disabilities and it was relatively easy to put Chronic Kidney Disease and specifically those needing dialysis treatment or kidney transplantation in the disability bucket.
- Some key senators including Senator Russell Long, the Senate Finance Committee Chair, were very interested in national catastrophic health insurance and felt that coverage for ESRD treatment was a “pilot for catastrophic health insurance”.
- There was a “Tipping Point” of public awareness about dialysis as a life-saving treatment. There were enough people living on dialysis, families living with ESKD, and nephrologists experiencing the distress of not having enough access to dialysis to provide voice and visibility to this hardship.

Stories of experience with limited access to lifesaving care from lack of funding provided powerful human stories. People able to tell these stories were organized into active advocacy groups. People of influence, Mamie Eisenhower, politically connected physicians, powerful legislators, were organically activated in political discourse and committees. Surely it was fortuitous that it was an election year and Medicare legislation was happening anyway. In addition, those legislators who may not have been focused on kidney treatment were willing to use it as a stepping stone to their greater goal of national catastrophic health insurance.

The joint House and Senate Conference Committee met between October 12 – 14, 1972 and agreed to include the Kidney Disease provision offered in the Senate version of the bill as Section 299I in the Social Security Amendments of 1972. The completed bill was adopted by the House and Senate and signed into law by then President Richard Nixon on October 30, 1972, just before Election Day, November 7, 1972.

Right time, right people, right place...a confluence of influence... gave us an ice bucket moment in kidney disease treatment history.