

The 50th Anniversary of the Implementation of PL 92-603: A Major Change in the Care of Patients with End Stage Kidney Disease

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In October 2022, the kidney community recognized the 50th anniversary of the passage of PL 92-603, which deemed chronic renal disease to be a disability and extended Medicare coverage for treatment of end stage renal disease (ESRD) to more than 90% of the United States population (U.S. Congress, Conference Committee, 1972). Its passage was a combination of strategy, timing, politics, an increasingly more vocal lay and professional kidney community (including First Lady Mamie Eisenhower who was a member of the National Kidney Foundation Board), and drama (a demonstration of hemodialysis at a U.S. House of Representatives Ways and Means Committee meeting). It was considered by many to be the pilot for national health care. A detailed description of what occurred (including the intrigue) written by Richard Rettig (1991) is available online (<https://nap.nationalacademies.org/catalog/1793/biomedical-politics>).

Before Implementation of PL 92-603

Prior to the passage of PL 92-603, the number of individuals needing treatment for ESRD far outnumbered the availability of equipment and was severely limited by the money available to pay for the treatment. Some centers had resorted to selection committees to determine, as a *Life* magazine article said, who lives and who dies (Alexander, 1962). All of that changed 50 years ago in July 1973 when PL 92-603 went into effect.

Joann Albers (2009), one of the nation's first nephrology nurses, described the care of patients with ESRD before PL 92-603:

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Fifty years ago, in July 1973, providing care to patients with end stage kidney disease changed dramatically with the implementation of legislation (PL 92-603) that deemed chronic renal disease to be a disability and provided coverage under Medicare for the treatment of the disease. In this article, we discuss the impact of the implementation of PL 92-603.

Keywords:

End stage kidney disease, Medicare, legislation, chronic kidney disease, chronic renal disease.

There was no money, but somehow or another, we just thought if we just kept going it was going to be okay, and that was [Dr.] Scribner's schizophrenic part, and it was good, because if he had looked at things totally rationally and decided to just do what seemed doable, none of this would have happened, because you simply had to just have the faith that you could keep going, and somehow we just did. I mean, you would come and say we're going to run out of money in 3 months. It was true, and the nurses would just work harder and harder to try to cut the cost down, and have the doctors do less, and do it with fewer people, and it did work. (p. 7)

Dr. John Bower (2008), describing the time before PL 92-603, said:

Oh, those were some tough days. You had to be between 15 and 50. If you were over 50 we wouldn't even consider you for dialysis. You had to be cooperative with the treatment. You had to be able to furnish your own transportation because we were only doing dialysis at the center at that time. You couldn't have any co-morbid conditions; we wouldn't take a diabetic, wouldn't even have looked at it.

Box 1

Public Law 92-603, 92nd Congress, H.R. 1 October 30, 1972

Chronic Renal Disease Considered to Constitute Disability

Sec. 2991. Effective with respect to services provided on and after July 1, 1973, section 226 of the Social Security Act (as amended by section 201(b)(5) of the Act) is amended by redesignating subsection (e) as subsection (f), and by inserting after subsection (d) the following new subsection:

“(e) Notwithstanding the foregoing provisions of this section, “every individual who –

“(1) has not attained the age of 65;

“(2) (A) is fully or currently insured (as such terms are defined in section 214 of this Act), or (B) is entitled to monthly insurance benefits under title II of this Act, or (C) is the spouse or dependent child (as defined in regulations) of an individual who is fully or currently insured, or (D) is the spouse or dependent child (as defined in regulations) of an individual entitled to monthly insurance benefits under title II of this Act; and

“(3) is medically determined to have chronic renal disease and who requires hemodialysis or renal transplantation for such disease; shall be deemed to be disabled for purposes of coverage under parts A and B of Medicare subject to the deductible, premium, and copayment provisions of title XVIII.

“(f) Medicare eligibility on the basis of chronic kidney failure shall begin with the third month after the month in which a course of renal dialysis is initiated and would end with the twelfth month after the month in which the person has a renal transplant or such course of dialysis is terminated.

“(g) The Secretary is authorized to limit reimbursement under Medicare for kidney transplant and dialysis to kidney disease treatment centers which meet such requirements as he may by regulation prescribe: Provided, that such requirements must include at least requirements for a minimal utilization rate for covered procedures and for a medical review board to screen the appropriateness of patients for the proposed treatment procedures.”

If we went through that initial screen, then we went to the next level and this was modeled after Scribner's. We had an anonymous committee... We would actually discuss the social worth. I still think of the night that we decided we couldn't take a little girl. She was 19 years old, a music major, but we didn't have enough openings and so we decided to take a 29-year-old man who was a salesman who had two small boys and his wife was a nurse and was willing to help and so we selected him. (p. 26)

Dr. Eli Friedman (2008) described what he called the ‘terrible time’ before PL 92-603:

Being unable to treat patients, having to not treat patients because of their age, having to limit therapy because of citizenship or other reasons that just didn't make sense. It was a very tough circumstance to watch people die, in

whom you knew you could interdict the fatal process but were unable to because of economic, political, or sociologic reasons that were beyond your control. (p. 48)

Implementation of PL 92-603

Passing the legislation was the first step in providing coverage for ESRD; implementing the legislation would take some time. To begin with, as Dr. John Sadler (2007) noted, “the folks at Medicare discovered in December that they had 7 months to put into play a completely new program about something they knew nothing about” (p. 23). But he added that clinicians did not know how to make policy: “I don't think there was a nephrologist in America who understood what the phrase ‘health policy’ meant and so we had no idea about policy making or how regulations were written, how laws were implemented” (p. 24). Medicare began their learning by spending time in successful dialysis centers in Seattle and Baltimore. To their credit, the Department of Health, Education, and Welfare convened a multidisciplinary Chronic Renal Disease Group to work on the implementation in February 1973. The American Nephrology Nurses Association (ANNA, then called the American Association of Nephrology Nurses and Technicians [AANNT]) was an invited participant. The letter of invitation to ANNA President Betty Preston (Oates), said:

This is to confirm arrangements for the conference scheduled for February 8 and 9 in regard to the chronic renal disease provision of the Social Security amendments of 1972. We are very happy that you will be able to review with us some of the issues associated with administering this provision... I am enclosing a copy of the law and of the report in the Congressional Record of the floor debate on the amendment—as well as a list of questions developed by the staff here which may help define the issues the Medicare program must resolve. As you can see, policies and processes have to be developed and integrated into the existing systems for determining the individual's entitlement, defining covered services, and making appropriate payment—and, in accordance with the provision of the law for applying standards of minimal acceptable utilization, establishing such standards and determining which institutions meet them.

The agenda included conditions of participation for dialysis and transplant, coverage policy, bill review standards, and reimbursement policy. AANNT representatives shared AANNT's *Standards of Hemodialysis* with meeting attendees and the Social Security Administration's Standards Committee.

Change was also happening in nephrology-related associations. AANNT, formed in 1969, was already expanding by the time PL 92-603 was passed, holding national meetings, creating new chapters throughout the country, and providing continuing education opportunities for nurses and technicians. At the AANNT national meeting in 1973,

several hundred more people attended than had been anticipated, requiring the association to double the size of their originally scheduled meeting room. In 1973, AANNT began working with other nephrology-related organizations and associations to improve education and originate certification for nephrology personnel.

Implementation was a Herculean task. The first draft of the regulations came out in June 1973, less than a month before implementation was to begin. The reaction of the nephrology community was not positive. As described by Dr. Sadler (2007):

We had a fit. They [Medicare] didn't know how to handle machinery because their durable medical equipment rules were just inappropriate to what we were doing and they hadn't changed them. They didn't know what to do with consumables because they had never had a service that used so much consumables. They didn't know how to pay doctors. (p. 24)

To no one's surprise, money was a major area of disagreement. The initial regulations mandated that Medicare pay the physician's fees to the dialysis unit, which would then pay the physicians, not the model the physicians were accustomed to, which was direct payment. The reimbursement rate for outpatient dialysis did not change in the first decade of the ESRD program, remaining at \$138 (with no adjustment for inflation) until 1983, when it was lowered (Institute of Medicine [IOM], 1991).

The first years of implementation were tumultuous, filled with uncertainty, and sometimes chaotic, as clinicians and Medicare, each with their own knowledge, expertise, and perspectives, tried to resolve the issues. Discussions about the need for changes in the regulations began immediately. The final federal regulations for the implementation of PL 92-603 were not published until three years later on September 1, 1976. The regulations were updated in 1978 and again in 1981, indicating that the provision of care to patients with ESRD and how it was organized and paid for were continuously changing.

Accounts from Nurses Who Were There

Betty Preston Oates, BSN, ANNA President, 1973

This year marks the 50th anniversary of the implementation of Public Law 92-603. On February 8 and 9, 1973, Mary O'Neill and I represented our organization (AANNT) at the Chronic Renal Disease Group Conference held at the Social Security Administration in Baltimore, Maryland. I'd like to give you some history prior to this law, then an overview of what the care of a nephrology patient was like prior to that time.

In 1965, the U.S. Public Health Service (PHS) started the Kidney Disease Control Program (KDCP). This program awarded 12 grants to establish dialysis centers across the country. When Dr. John Bower came to the

University of Mississippi Medical Center in 1965, he applied for and received one of the 12 grants to study dialysis. His grant was for \$493,080 to build and operate a hemodialysis unit for 3 years. In 1966, University Medical Center in Jackson, Mississippi, opened the state's first dialysis unit. Patients were selected for the program by a committee. Patients (some from 3+ hours away) came to Jackson to dialyze twice a week for 12 hours. They were real pioneers. Knowing our funding from the grant would be coming to an end, Dr. Bower established a home training program, funded by Vocational Rehabilitation. Beginning in June 1969, patients and their helpers were trained, and began to go home with equipment and one year of supplies. In one area of our state, a trailer was set up next to the hospital, and several home-trained patients went there to do their own dialysis. This permitted a sharing of equipment.

In 1972, Dr. Bower was one of several nephrologists who were present in Washington, DC, during the hearings. He was with Virgil Smirnow, Executive Director of the National Kidney Foundation, when Virgil testified before Congress. Section 2991 of PL 92-603 passed on October 30, 1972. The program's launch was July 1, 1973. This law extended Medicare coverage to Americans if they had stage 5 chronic kidney disease, and were otherwise qualified under Medicare's work history requirements. Our program grew through the placement of limited care facilities (Kidney Care) in towns around the state. Dr. Bower's long-term goal was to establish dialysis facilities within 30 miles of any patient's home. Nurses and technicians from those areas of the state came to Jackson for training. Over a period of 23 years, Kidney Care opened dialysis facilities in 22 different cities in Mississippi. What did this mean to our patients with ESRD? It meant no more selection committees, no more rationing of care to only those between the ages of 15 to 50 years, no more lengthy commutes for the patient to get to a dialysis facility, and more lives were saved.

What did this mean to nurses? It meant a greater demand for nurses trained in the care of the patient with ESRD. As new nurses came into the field of nephrology, they needed education and support. We learned during the mid-1960s that nurses had a desire and need to exchange information with other nurses. Until our organization was formed, many of us were fortunate enough to work for physicians who would take us to their conferences (e.g., American Society of Artificial Internal Organs [ASAIO], Southeastern Dialysis and Transplant Association [SEDTA]). We were able to have some separate sessions for nurses. In 1969, we had a Nursing Symposium on Dialysis and Renal Transplantation in Atlantic City. At the end of that meeting, our organization was born. Our original name was the American Association of Nephrology Nurses (AANN). Bernice Hinckley, nurse consultant with the Kidney Disease Control Program, was elected our first president. ANNA continues to support nephrology nurses through an annu-

al symposium, conferences, scholarships, grants, and our great publication, the *Nephrology Nursing Journal*.

The implementation of PL 92-603 had a far-reaching impact on patients with ESRD as well as those who care for them.

Caroline Counts, MSN, CNNe, ANNA President, 2003-2004

My career in nephrology nursing began on August 23, 1970 – two years before the passage Section 2991 of Public Law 92-603, previously described. I was recruited to work in the Hemodialysis Unit at the Medical University of South Carolina (MUSC) by Dr. Arthur V. Williams, one of the pioneers in nephrology. During his residency years at Marquette University School of Medicine in Milwaukee, Dr. Williams worked with the Developmental Division of Allis-Chalmers to help design the Kolff-type artificial kidney.

The first day I actually worked in the unit, I wondered what I had gotten myself into. I saw large machines with a lot of tubing that reminded me of spaghetti. It was a three-bed unit that utilized the Travenol RSP™ equipment. My mantra became, “If people with no medical background can perform these treatments at home, I – a Registered Nurse – can do it!” At the time, the approximately 50 patients who had been trained at MUSC completed their treatments at home with a partner, usually a spouse or parent. They were located throughout South Carolina. There were zero outpatient dialysis facilities in South Carolina. It was estimated that for every one patient we treated, another five citizens died never having received dialysis or transplant.

There were some regional funds that helped offset the costs of running the unit; however, there were no steady sources of funding for the patients’ home treatments, a cause of anxiety for all. Generally, private insurance policies did not cover the cost of the ‘experimental’ treatments. Each individual patient raised money for supplies through a variety of fundraisers, such as activities sponsored by the person’s church, fish fries, collecting Betty Crocker stamps, etc. It never ended. A social worker was available to provide guidance and emotional support, but the patient carried the ultimate responsibility for fundraising. The funding that came with PL 92-603 was a Godsend.

Before the implementation of PL 92-603, the patient population tended to be young, ranging from age 18 to mid-40s. Additional exclusion criteria for acceptance into the program included diabetes, uncontrolled hypertension, or any other major medical issue. In other words, except for having glomerulonephritis or another kidney disease, the patient was healthy and young. This seemed to be true in other areas of the country as well. Changes came following the enactment of the federal legislation changes. From a national perspective in the early 1970s, the number of patients was expected to increase sharply and then level off to approximately 40,000 by 1977 (IOM, 1991). This was a major underestimation of the need.

Moreover, the primary diagnosis began switching from glomerulonephritis to diabetes and hypertension (IOM, 1991). Other major medical conditions were no longer a stumbling block to receiving treatment – another key change for individuals with kidney disease and not just in our geographical area. Acceptance criteria had been liberalized. As a result, not only had the size of the population increased, but the characteristics of the patients also changed. For example, the number of patients who were elderly increased radically.

The changes heralded by Section 2991 of Public Law 92-603 were monumental and required changes in every aspect of providing care to our patients. Challenges were met head on and required expanding knowledge to meet the needs of a growing patient population. The adage “learning never ends” certainly came into play.

Geraldine Biddle Moore, RN, CNNe, CPHQe, ANNA President, 1985-1986

The impetus for the ESRD program began in the 1960s, when it first became possible to save the lives of patients whose kidneys had failed. But dialysis was new, experimental, and costly, with limited facilities that could not possibly accommodate the numbers of individuals who could benefit.

I started working in dialysis in January 1968 at Thomas Jefferson University Hospital in Philadelphia. Dialysis training existed for resident physicians, and a few patients were receiving peritoneal or hemodialysis treatments. I had to learn what was known about the science of the dialysis procedure from the renal fellows, and company representatives taught everyone about the dialysis equipment. A patient selection committee existed. I and two other dialysis nurses participated on the committee in rotation. As others have described, only the young, healthy, productive members of society were considered acceptable candidates for the coveted lifesaving treatments.

There were risks associated with working in dialysis. I started as a “replacement” nurse – the entire dialysis unit staff had been infected with hepatitis B with some deaths. Research from this and other outbreaks would be instrumental in the identification of the hepatitis B surface antigen (referred to as the Australian Antigen at the time) and the subsequent description of universal precautions. In 1977, the Centers for Disease Control and Prevention (CDC), Viral Hepatitis Surveillance Activity, described “Control Measures for Hepatitis B in Dialysis Centers” (CDC, 1977). In 1979, AANNT published a supplemental edition of the journal, “Hepatitis B As An Occupational Risk For Nephrology Nurses and Technicians.” These control measures became a significant component of the new ESRD regulations.

During the 1960s, dialysis was highly publicized as a heroic and dramatic procedure. The cost of dialysis, however, was nearly \$40,000 a year for each patient. Payment for the treatment was only available through limited research grants or private funds. As was pointed out in

newspaper and magazine articles at the time, choices had to be made as to which patients should be offered dialysis.

In 1972, when the amendment to provide federal funds for dialysis or kidney transplant was being debated, the senators were all too aware of the ethical problems that arise when doctors or lay committees must decide how to allocate scarce medical resources. The mantra through the halls of Congress echoed the strain that the only thing standing in the way of more machines was money – not technology. The decision to start the ESRD program was founded on humanitarian motives.

Like other programs in which it was ‘only a question of money,’ the creation of the ESRD program quickly proved to haunt the government with a set of perplexing problems, not the least of which was – and continues to be – tremendous growth in costs. As reported by Dr. Blagg (2007):

Estimates of the cost of the kidney provision were widely off. According to the NKF, the cost would be \$35 to \$75 million the first year; The Social Security Administration Office of the Actuary, which had had little time to come up with figures, estimated \$100 to \$500 million the first year, increasing substantially in succeeding years. Senator Hartke quoted estimates for hospital dialysis at \$22,000 to \$25,000 per year, \$17,000 to \$20,000 for center dialysis, and \$19,000 for the first year of home dialysis with a subsequent cost of about \$5,000 per year, 85% success rate for kidney transplants and a substantial future reduction in the \$5,000 cost of transplant. Hartke also expected costs would continue to fall with technological advances and more transplants. (pp. 492-493)

Impact of Implementation

When the ESRD program was implemented in 1973, less than 10,000 patients received ESRD benefits (IOM, 1991). In 1974, the first full year of the program, the number of patients had increased to 15,993 patients, with a Medicare cost of \$299 million (IOM, 1991). Five years later in 1979, the number of patients funded by Medicare had increased to 52,184, the number of new (incident) patients had increased to 16,937, and the Medicare ESRD costs topped \$1 billion (IOM, 1991). By 1980, the number of patients with ESRD had increased to 67,493 and was projected more than double by 1990 to 149,868 (IOM, 1991). That number would prove to be a gross underestimate.

Prior to the enactment of federal funding for ESRD, strict criteria were enforced by selection committees in accepting patients into treatment programs. Treatment goals were to treat and rehabilitate each patient to return to a productive role in society. Candidate selection criteria often included ability to pay for treatment, main income earner, psychologically stable, no other comorbidities (cancer, diabetes, physical disabilities, etc.), and willingness to go on home dialysis. When Medicare began paying for dialysis, all previous barriers to treatment began to disappear – treatment for ESRD was now an entitlement, available to almost all in need.

An immediate growth in the number of dialysis facilities took place around the country. When the ESRD program was implemented in 1973, there were 606 dialysis units in the United States, a number that doubled in the first 10 full years of the program to 1217 (IOM, 1991). The ESRD program also required reasonable access to care, and because dialysis units were few and far between, a plan for controlled growth was also needed. ESRD Network Coordinating Councils were conceived and written into the initial regulations to administer and support the ESRD program. They initially served as monitors and assurers of regional growth (a dialysis facility needed to be available with 50 miles of a patient population). They were also charged with collecting basic demographic information and establishing Medical Review Boards to oversee quality.

At first, the growth of dialysis services took place in hospital-based units, later migrating out of hospitals to free-standing, chronic outpatient facilities. National Medical Care emerged as the first for-profit dialysis chain (Kolata, 1980b).

Rehabilitation was promoted as an ESRD program goal. In 1972, Senator Vance Hartke made the following statement in the Senate as he debated the amendment that established the ESRD program: “69% of those on dialysis can return to work but require retraining and most of the remaining 40% need no retraining whatsoever. These are people who can be active and productive, but only if they have the life-saving treatment they need to badly” (Blagg, 2007, p. 493).

However, despite significant efforts put forth by dialysis staff to encourage continued employment or rehabilitation programs, the patient population changed in significant and unanticipated ways with the new program funding. In a 1980 article, Dr. Blagg, then director of the Northwest Kidney Center in Seattle, commented, “It used to be unheard of for elderly and very sick patients to be dialyzed” (Kolata, 1980a, p. 473). Dr. John Sadler, of the University of Maryland Medical School in Baltimore, made the following comments about the start up of the ESRD program: “We had [in 1972] what was in many ways an idealized population. A large fraction of the patients was in a productive period of their lives. They were young and (apart from their kidney failure) had little else wrong with them” (Kolata, 1980a, p. 473).

With payment available for almost all, the number of patients on dialysis grew steadily through the 1970s as did the age of patients being accepted into programs and their accompanying comorbidities. The percentage of patients with ESRD who were age 65 years or older was 5% in 1973, 24% in 1978, and 33% in 1983 (IOM, 1991). Increasingly, more and more elderly patients with conditions such as diabetes, cancer, and heart disease populated dialysis units. Ethical questions arose about suitability for treatment. Legal arguments arose around entitlement to treatment and termination of dialysis. By the end of the decade, physicians and other health care specialists were

publicly disturbed by the increasing number of terminally ill or incompetent patients who were being dialyzed.

The numbers of patients performing home dialysis (which had been a requirement for program acceptance in the 1960s) gradually declined. In 1972, 40% of the 4953 patients on dialysis in the United States were on home dialysis (Bryan, 1976). With the ESRD Program, reimbursement for both the dialysis treatment and physicians was far less for home dialysis. Patients and family members chose to receive treatment in outpatient dialysis centers, not wanting the responsibility or “mess” at home. Many dialysis centers stopped offering home training, preferring to have patients come to their centers.

By the end of the decade, complaints about the program were surfacing from patients, physicians, and other advocacy groups (Kolata, 1980a). Patients said that dialysis facilities were centralized and “to switch from one to another often required commuting a long distance, which could be especially difficult for sick patients;” some said their physicians “were insensitive to their complaints and told them bluntly that if they were unhappy, they could leave. Others said that they were afraid of their doctors since their very lives depended on the doctors’ good graces” (Kolata, 1980a, p. 474).

Kolata (1980a) reported that “a number of physicians and health care specialists believed that the government is remiss in not keeping tabs on quality of care. There is no way to identify centers with abnormally high mortality rates, for example, since even such minimal data are not available” (p. 476). Drs. Sadler and Blagg were both politically involved in the design of the ESRD Program and were later vocal critics. With knowledge of the types of data the government had in its computers, Dr. Sadler commented, “We have told the government for the past 8 years how to measure quality of care. He concluded that the federal bureaucracy was not set up to deal with this matter” and Dr. Blagg agreed. “The government talks about quality of care but it hasn’t done anything yet to measure it” (Kolata, 1980a, p. 476).

Nephrology Nursing Before and After the Implementation of PL 92-603

Nephrology nurses who began their nephrology practice in the 1960s and early 1970s remember the lived experiences, challenges, and heartaches that accompanied caring for patients before the ESRD Program came into existence. We remember the excitement, challenges, and thrills that accompanied changes in dialysis units that were a result of PL 92-603, as increasing numbers of new patients, new physicians, new nurses, new equipment, and support staff arrived each year. There were chal-

lenges in moving from hospital-based units to free-standing dialysis units, the fun of working with architects and other planners in designing new units, and the academic stimulus of learning about new technologies and being the primary “influencer” when it came to selecting products for purchase.

Yes, for nephrology nursing, there were often complications, crises, and chaos present during the 1970s, but it was also a period of exquisite growth and development. It was special to be a dialysis nurse, a transplant nurse, a nephrology nurse – and it was fun.

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