Chapter Eight
Pediatric ESRD

Our judgement does not reckon in their exact and proper order things which have come to pass at different periods of time; for many things which happened many years ago will seem nearly related to the present, and many things that are recent will seem ancient, extending back to the far-off period of our youth. And so it is with the eye, with regard to distant things, which when illumined by the sun seem near to the eye, while many things which are nearer seem far off.

Leonardo da Vinci
Pediatric end-stage renal disease (ESRD) patients pose unique challenges to providers and to the healthcare system, which must address not only the disease itself in these patients, but the many extra-renal manifestations that affect their lives and their families. Nowhere are these more evident than in the growth of children with kidney disease. On the next page we illustrate the distribution of pediatric patients by height, as determined from dialysis service claims that now require the reporting of height and weight for the adjustment of payments to dialysis units. In the incident pediatric population, 52 percent of patients have a height in the lowest quintile of the general population, while 32 percent are in the lowest weight quintile. In the prevalent population, two-thirds of patients are in the lowest height quintile of the general population and 50 percent are in the lowest weight quintile. In prior ADRs we have shown that, despite these realities, there is relatively low use of growth hormone. There appears to be limited progress in this area of growth and development, particularly with prevalent patients slipping farther behind their counterparts without kidney disease. Several factors may limit the use of growth hormone in this challenged population, including payor coverage, but this treatment is within an FDA-labeled indication of some products for which Medicare does provide coverage. In the future, the USRDS Coordinating Center will assess these treatments in Medicare and employer group health plan data to determine rates of use. 

The overall incidence of ESRD in the pediatric population has been relatively stable since 1988, and there is evidence of a decline since 1996 in ESRD due to glomerulonephritis. It is not clear if these trends may be influenced by treatments with ACE-Is or ARBs, a question which merits investigation. 

In 2007, approximately half of all incident pediatric ESRD patients initiated therapy on hemodialysis, and its use has remained steady during the last five years. In the prevalent pediatric population, 71 percent of patients are being sustained with a kidney transplant.

Data from the revised Medical Evidence form assess pre-ESRD nephrology referral, dietitian care, use of dialysis catheters, and lipid levels in the incident population. Both nephrology care and dietary counseling prior to ESRD, for example, are more likely among children age 0–9 and 10–14 than among adult patients. Challenging to understand, however, is the lower rate of nephrology referral for children with glomerulonephritis and secondary glomerulonephritis compared to adults with comparable disease. The lack of dietary counseling among pediatric patients is also lower than expected, given that ESRD affects children to a greater extent than adults in terms of growth and development. The lack of dietary counseling among pediatric patients is also lower than expected, given that ESRD affects children to a greater extent than adults in terms of growth and development. Medical Evidence form data also show that mean hemoglobin levels at initiation in pediatric patients are close to 10 g/dl, with 29–48 percent of children receiving an erythropoiesis stimulating agent (ESA) to treat their anemia prior to ESRD. Children age 15–19 and those with secondary glomerulonephritis receive the least amount of treatment with ESAs. Influenza and pneumococcal pneumonia can, of course, lead to increased hospitalization rates and higher risks of mortality. Rates of vaccination against these diseases have
improved in the pediatric population, but still remain far below recommended levels. And there continue to be discrepancies in vaccination rates by modality, with hemodialysis patients more likely to be vaccinated than children on peritoneal dialysis or with a transplant. Vascular access at the initiation of dialysis is an issue of great concern, since starting dialysis is a very dramatic change in a child’s life and for his or her support system. Anxiety over needle sticks, transplant surgery workups, and dietary issues can be overwhelming to children and families. Catheter complications, however, pose significant hazards to children, and need to be addressed with providers and family members. Major central vein thrombosis is an ongoing source of adverse events that alter central circulation, and needs to be weighed against the continued use of catheters. As discussed in the 2007 and 2008 ADRs, and in contrast to the adult population, there has been no progress in the five-year survival of pediatric ESRD patients over the last ten years. In some populations, in fact, the likelihood of survival declined slightly between the 1993–1997 and 1998–2002 periods. These observations suggest a need for greater attention to risk factor management and vascular access choice. The most striking findings related to pediatric patients center on this lack of improvement in patient survival over the past decade, a central concern, as it suggests that care of this population is insufficient. Both infectious and cardiovascular complications are high, with the latter being the main cause of death in this young population. Lipid levels are high, yet the amount of monitoring and treatment is unclear. And high heart failure rates may reflect the long-term burden of hypertension and fluid overload. These are not new challenges, but the community will need to assess them and develop new approaches to improving outcomes in this vulnerable population.

Figure 8.1: see page 375 for analytical methods. Incident & prevalent hemodialysis patients age 0–19. Quintiles based on general U.S. pediatric population.
The number of children initiating ESRD therapy with a primary diagnosis of glomerulonephritis decreased nearly 6 percent between 1998–2002 and 2003–2007, from 1,657 to 1,563, while the numbers with secondary glomerulonephritis or cystic kidney disease both rose 15 percent overall, from 639 to 732 and 1,836 to 2,107, respectively. **Figure 8.2. Incident ESRD patients age 0–19.**

The number of new pediatric ESRD patients has increased 6.1 percent since 2000; growth in the rate of new cases per million population (adjusted for age, gender, race, and primary diagnosis), however, has slowed since the 1980s, to just 2.8 percent since 2000. In 2007, 1,245 children started ESRD therapy, for a rate of 14.6 per million population. **Figure 8.3; see page 375 for analytical methods. Incident ESRD patients age 0–19.**

The prevalent rate of pediatric ESRD has nearly tripled since 1980, yet this growth appears to be slowing, with a modest increase of 11.4 percent since 2000. In 2007, 7,209 pediatric patients were receiving ESRD treatment, at an adjusted rate per million population of 84.6. The number of transplant patients has grown nearly 19 percent since 2000. **Figure 8.4; see page 375 for analytical methods. December 31 point prevalent ESRD patients age 0–19.**
Since 2000, the adjusted rate of new pediatric ESRD cases caused by glomerulonephritis has fallen 12 percent, to 3.3 per million population. For cystic/hereditary/congenital disease, in contrast, the rate has grown nearly 16 percent (to 5.0), while the increase for ESRD caused by secondary glomerulonephritis has been a more modest 5.2 percent (to 1.6). (Figure 8.5; see page 375 for analytical methods. Incident ESRD patients age 0–19.

In the pediatric ESRD population, the rate of prevalent cases caused by cystic kidney disease continues to rise — 27 percent since 2000, to 36.4 per million population. The rate of ESRD due to secondary glomerulonephritis has seen a similar increase of 23 percent during this period, to 6.7 per million. The rate of ESRD due to glomerulonephritis, in contrast, has fallen 9.4 percent, to a rate of 17.3 per million population. (Figure 8.6; see page 375 for analytical methods. December 31 point prevalent ESRD patients age 0–19.
When compared to those of adults, the odds of being under the care of a nephrologist prior to ESRD are 61–72 percent higher in children age 14 and younger, and 6.0 percent lower in those age 15–19. Pre-ESRD dietary care is 3–7 times more likely in children than adults, and older children are more likely to be informed of their transplant options than adults or children age 0–9. \( \text{Table 8.a. Incident ESRD patients age 0–19. *Cystic/hereditary/congenital disease.} \)

In the pediatric ESRD population, the odds ratio of a cholesterol level above 170 mg/dl at the beginning of ESRD therapy is 15 percent greater for African American children, and 37 percent lower for white children, than for children of other races. Children of other races, in contrast, are the most likely to have a triglyceride level above 150 mg/dl at initiation. By primary diagnosis, children with cystic/hereditary/congenital disease are the least likely to have an elevated lipid level, and those with secondary glomerulonephritis the most likely. \( \text{Table 8.b. Incident ESRD patients age 0–19. *Cystic/hereditary/congenital disease.} \)

By age, the estimated glomerular filtration rate (eGFR) ranges from 11.3 to 13.2 ml/min/1.73 m\(^2\) in children initiating ESRD therapy. Whites have slightly higher eGFRs than African Americans and those of other races, at 12.2, 11.9, and 11.1, respectively. By primary diagnosis, eGFRs are highest in children with secondary glomerulonephritis, at 13.0. \( \text{Figure 8.7. Incident ESRD patients age 0–19, 2007, with new (revised edition) Medical Evidence forms. *Cystic/hereditary/congenital disease.} \)
Mean hemoglobin levels at initiation are highest in children age 0–9, at 10.15 g/dl, and more than 0.5 g/dl lower in those age 15–19, at 9.58. By race, levels are highest in whites, at 9.94 g/dl, compared to 9.7 and 9.57, respectively, in African Americans and children of other races. Children with cystic/hereditary/congenital disease have a mean level of 10.42 g/dl, compared to 9.54 and 9.01 in those with glomerulonephritis or secondary glomerulonephritis.

The use of erythropoiesis stimulating agents (ESAs) prior to the start of ESRD therapy is highest in children age 10–14, whites, and those with cystic/hereditary/congenital disease, at 48.1, 40.0, and 54.1 percent, respectively.

The mean monthly hemoglobin in the pediatric population rose from 9.1–9.4 g/dl in 1991 to 11.5–11.9 in 2007; this growth parallels a rise in the mean weekly EPO dose, which reached approximately 17,400 units at the end of 2007.

Children age 15–19 are more likely to receive IV iron than their younger counterparts, yet iron use in children with ESRD remains lower than use among adults. Children on hemodialysis are nearly four times more likely to receive IV iron than those on peritoneal dialysis. See page 375 for analytical methods.
Vaccination rates for influenza in the pediatric population have improved, yet still remain far from the Healthy People 2010 goal of 90 percent. In 2000–2003, 23 percent of pediatric ESRD patients received a vaccination; this rose to 32 percent in 2004–2007. Children on hemodialysis are the most likely to be vaccinated, at 40 percent in the most recent period compared to 32 and 25 percent in those on peritoneal dialysis or with a transplant. And vaccination rates are slightly higher in the white population than among African Americans.

The rate of pneumococcal pneumonia vaccinations during a two-year period has grown only slightly since 2000–2003, from 5.8 to 8.8 percent overall. The rate of 13.5 percent in the hemodialysis population is three times greater than the 4.5 percent seen among pediatric patients with a transplant.

In most populations, vaccinations against hepatitis B fell slightly between 2000–2003 and 2004–2007, and the overall rate fell from 7.6 to 7.0 percent. Rates are again highest in the hemodialysis population, at 14.2 percent. The only increase appeared in African American children on hemodialysis, 15.3 percent of whom were immunized against hepatitis B in 2004–2007.

It is important to note that data on vaccination rates in children with ESRD should be interpreted with caution, as claims data may not completely track all vaccinations. 

\( \text{FIGURES 8.12–14; see page 375 for analytical methods. Point prevalent ESRD patients age 0–19.} \)
Catheters are the most common first access in children initiating dialysis. In those not under the care of a nephrologist prior to ESRD, catheter use reached 63.6 percent in 2007, while in those seeing a nephrologist for 0–12 or greater than 12 months prior to ESRD, rates were 42.8 and 34.9 percent, respectively. Figure 8.15; see page 376 for analytical methods. Incident hemodialysis patients age 0–19.

Since 2001–2003, the use of arteriovenous fistulas among new pediatric hemodialysis patients has increased slightly, from 19.6 to 22.3 percent. Most patients begin therapy with a catheter — 74 percent overall, and nearly 88 percent of those with cystic kidney disease. Figure 8.16; see page 376 for analytical methods. Incident hemodialysis patients age 0–19; ESRD CPM data. *Cystic/hereditary/congenital disease.

Event rates for infection and sepsis among new pediatric hemodialysis patients with a catheter rose 66 and 133 percent, respectively, between 2001–2003 and 2004–2006, to 200 and 181 events per 100 patient years. Because patient counts are small, particularly for fistula and graft events, care should be taken when interpreting these data. Figure 8.17; see page 376 for analytical methods. Incident hemodialysis patients age 0–19; ESRD CPM data.
Adjusted all-cause hospital admission rates in the pediatric population increase steadily through the first twelve months of dialysis, a finding that has remained consistent over time. In the 2002–2006 cohort, during months 9–12, rates in children age 0–9 were 78 and 84 percent higher, respectively, than those found in children age 10–14 and 15–19. 

When compared to rates in 1997–2001, cardiovascular admission rates at the end of the first year of dialysis for pediatric patients initiating in 2002–2006 were 7–8 percent lower in children ages 0–9 and 10–14, and showed no difference in those age 15–19. Rates in all study intervals rose sharply in the first months of dialysis. 

For patients age 0–9 initiating dialysis therapy in 2002–2006, rates of admissions for infection were on average nearly three times higher than rates for cardiovascular admissions, while rates for those age 10–14 were nearly twice as high. Infectious hospitalization rates in children age 0–9 were two-fold higher than rates found in children age 10–19. 

Rates of hospital admissions for other causes in the first year of dialysis vary widely across study periods and pediatric age categories, but consistently rise during the year. For children age 0–9 initiating therapy in 2002–2006, the rate reached 1,441 per 1,000 patient years at risk, compared to 788 and 683 in those age 10–14 and 15–19. 

89. Adjusted cardiovascular admissions in the first year of dialysis, by age & year

10. Adjusted all-cause admissions in the first year of dialysis, by age & year

11. Adjusted admissions for infection in the first year of dialysis, by age & year

12. Adjusted admissions for other causes in the first year of dialysis, by age & year
For the first month of dialysis, the adjusted rate of all-cause mortality in pediatric patients has increased 84 percent since 1992–1999, reaching 45.6 deaths per 1,000 patient years in 2000–2006. At 21 deaths per 1,000 patient years, the rate of cardiovascular mortality in the first month is now 4.4 times greater than in the earlier period. **Figures 8.22–23**; see page 376 for analytical methods. Incident dialysis patients age 0–19.

Compared to that seen in 1992–1999, the rate of mortality from infection in the first month of dialysis was 2.3 times greater for children beginning therapy in 2000–2006, reaching 8.2 deaths per 1,000 patient years at risk. The rate of first-month mortality from other causes has not changed. **Figures 8.24–25**; see page 376 for analytical methods. Incident dialysis patients age 0–19.

There continues to be little improvement in five-year survival among pediatric dialysis patients, and for some cohorts — including hemodialysis patients age 10–14 — the probability of a child surviving these first years of therapy actually declined between 1993–1997 and 1998–2002. The probability of survival is lowest in the youngest patients, at 0.73 and 0.76 in hemodialysis and peritoneal dialysis patients age 0–9, respectively, compared to 0.82 in hemodialysis patients age 10 and older, 0.85 in peritoneal dialysis patients age 10–14, and 0.82 in peritoneal dialysis patients age 15–19. **Figure 8.26**; see page 376 for analytical methods. Incident dialysis patients age 0–19.
In 2007, 1,245 children started ESRD therapy, for a rate of 14.5 per million population. • 8.3

In 2007, 7,209 pediatric patients were receiving ESRD treatment, for a rate of 84.6 per million population. • 8.4

The prevalent rate of pediatric ESRD cases caused by cystic kidney disease has risen 27% since 2000, to a rate of 36.4 per million population. • 8.6

The odds of pre-ESRD NEPHROLOGIST care are 6.0% lower in children age 15–19 than among adults. • 8.8

By race, HEMOGLOBIN levels are highest in whites, at 9.9 g/dl, compared to 9.7 & 9.6, respectively, in African Americans & children of other races. • 8.8

The use of ESAs prior to the start of ESRD therapy is highest in children with CYSTIC KIDNEY DISEASE, at 54%. • 8.9

Children on hemodialysis are nearly FOUR TIMES more likely to receive intravenous IRON than those on peritoneal dialysis. • 8.11

Just 32% of pediatric ESRD patients were vaccinated against INFLUENZA in 2004–2007. • 8.12

CATHETERS are the most common access in children initiating dialysis, at 63.6% in children with no nephrologist care prior to ESRD. • 8.15

Infectious hospitalization rates in children age 0–9 were TWO-FOLD higher than rates found in children age ten & older. • 8.20


**summary**