



Cystic Fibrosis Research News

Citation:

Hoch H, Sontag MK, Scarbro S, Juarez-Colunga E, McLean C, Kempe A, Sagel SD. "Clinical outcomes in U.S. infants with cystic fibrosis from 2001 to 2012." 2018 Nov;53(11):1492-1497.

What was your research question? (50 words maximum)

How have clinical outcomes for children with cystic fibrosis (CF) changed since newborn screening for cystic fibrosis became universal in the United States?

Why is this important? (100 words maximum)

Early diagnosis of cystic fibrosis is essential, and newborn screening has helped more children to be diagnosed early in life. We wanted to see, as children were diagnosed earlier in life, if there were also improvements in growth, bacteria that they grow in their lungs, and other outcomes over the same time period. We also wanted to see if there were still areas where we could potentially improve.

What did you do? (100 words maximum)

We evaluated data from more than 8000 children up to two years old with CF from 2001-2012. We looked at changes in growth, bacteria grown, and treatment with pancreatic enzymes over that time period to look for significant differences over time.

What did you find? (100 words maximum)

More children were diagnosed by newborn screening in 2012 than in 2001. Overall, we found significant improvements in weight, height, and weight for length during the study period. However, there is still room for improvement in nutrition for infants to allow adequate growth. Fewer children were diagnosed with *Pseudomonas aeruginosa* bacterial infections over time, but more children were diagnosed with *Staphylococcus aureus* infections.

What does this mean and reasons for caution? (100 words maximum)

Clinical outcomes for children with CF appear to be improving. While our research cannot directly link these outcomes to newborn screening, we observed that as newborn screening increased, outcomes improved. However, there remains room to improve nutritional and bacterial outcomes for patients.

What's next? (50 words maximum)

Further research is needed to evaluate how outcomes are changing over time, particularly as we develop more therapies that target children at an early age.