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Outcomes of infants born during the first 9 years of CF newborn screening in the United States: successes and the need for improvement

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Abstract

Introduction: Newborn screening (NBS) for cystic fibrosis (CF) was implemented in all US states and DC by 2010. This hypothesis generating study was designed to form the basis of additional research and to plan quality improvement initiatives. The aims were to describe the outcomes of infants with CF born during the first 9 years of universal NBS. Methods: We included participants in the CF Foundation Patient Registry born 2010-2018 with age at first CF event (first sweat test, clinic visit or hospitalization) by age 365 days. We assessed age of center-reported diagnosis, age at first CF event, demographics and outcomes for three consecutive 3-year cohorts born in 2010-2012, 2013-2015, and 2016-2018. Results: In 6354 infants, median age at diagnosis was earlier than median age at first CF event, which decreased from 1st cohort to 3rd cohort. Weight-for-age (WFA) was $<$ 10th percentile in about 40% of infants at the first CF Center visit. Median WFA z-score at 1-2 years was > 0 but height-for-age (HFA) z-score was < 0 through age 5-6 years. The second cohort had a higher HFA z-score than the first cohort at age 5-6 years. Pseudomonas aeruginosa infection rates decreased over time. About 1/3 of infants were hospitalized in the first year of life across cohorts. Conclusion: Over 9 years of CF NBS, median age at first CF event decreased. CF NBS had positive health impacts but improving nutritional deficits and reducing infant hospitalizations remain targets for improvement.

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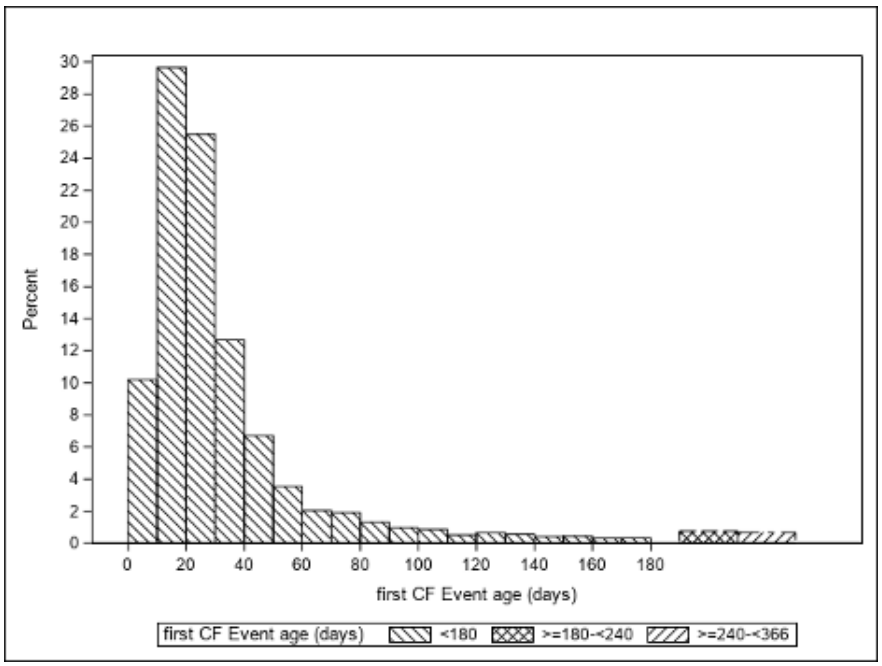

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