May 3, 2018

Colorado Senate Committee on Finance and Committee on Appropriations
200 E Colfax RM 346
Denver, CO 80203

RE: HB 18-1006 “Infant Newborn Screening”

As the world’s leader in the search for a cure for CF and an organization dedicated to ensuring access to high quality, specialized cystic fibrosis (CF) care, the Cystic Fibrosis Foundation writes in support of Colorado House Bill 18-1006, Infant Newborn Screening to ensure early detection, follow-up services, interventions, and referrals for infants with cystic fibrosis and other health conditions.

Cystic fibrosis is a life-threatening genetic disease that is diagnosed in 1 of every 3,500 newborns in the United States. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. Newborn diagnosis for cystic fibrosis is critical – infants with CF as young as two weeks of age suffer from malnutrition due to pancreatic insufficiency and intestinal malabsorption.¹ Nutrient deficiencies include essential fatty acids and vitamin E that are important in brain growth and development. Respiratory issues, including colonization with Pseudomonas aeruginosa, can occur early and cause significant pulmonary damage within the first year of life. Any delay in the diagnosis exposes CF infants to both increased morbidity and mortality.

A modernized newborn screening program is vital to helping ensure people with CF live full and productive lives. The bill helps ensure early diagnosis and appropriate follow-up care for infants born with CF by requiring timely screening for CF at all birthing facilities and coordination between the lab, care providers, and guardians.

In addition, newborn screening for CF continues to evolve. As Colorado revises and updates its policies regarding newborn screening, genetic counseling, and education in Colorado, we urge the state to regularly consult CF experts to ensure protocols and technologies follow current best-practices for CF screening, CFTR mutation testing, reporting, and referral.

The Cystic Fibrosis Foundation appreciates the opportunity to provide input on these important policy changes. We look forward to working with the state of Colorado to continually improve the infant newborn screening program, ensure timely access to high-quality, specialized CF care, and improve the lives of all people with cystic fibrosis. Please consider us a resource moving forward.

Sincerely,

Mary B. Dwight
Senior VP of Policy & Advocacy
Cystic Fibrosis Foundation

Lisa Feng, DrPH
Senior Director of Policy & Advocacy
Cystic Fibrosis Foundation