March 29, 2023

Senator Christine Rolfes
Chair
Ways & Means Committee
303 John A. Cherberg Building
PO Box 40423
Olympia, WA 98504

Senator Lynda Wilson
Ranking Member, Operating
Ways & Means Committee
205 Legislative Modular Building
PO Box 40417
Olympia, WA 98504

Senator June Robinson
Vice Chair, Operating
Ways & Means Committee
230 John A. Cherberg Building
PO Box 40438
Olympia, WA 98504

Senator Ann Rivers
Assistant Ranking Member, Capital
Ways & Means Committee
214 Legislative Modular Building
PO Box 40418
Olympia, WA 98504

Dear Senators Rolfes, Wilson, Robinson, and Rivers:

On behalf of the cystic fibrosis (CF) community in Washington, we write in support of the newborn screening fee increase to fund expanded CF DNA testing. Expanded newborn screening DNA testing for CF will improve timeliness of diagnosis and help address related racial and ethnic disparities.

The proposed fee increase will support expanded DNA testing by eliminating the second immunoreactive trypsinogen (IRT) analysis in Washington's CF newborn screening algorithm. Most states only perform one IRT analysis and eliminating the repeat IRT screen will help facilitate more timely diagnoses for babies born with CF. Studies show that repeat IRT screens can lead to preventable delays in diagnosis, inequities because of delays in the collection of the second specimen, and inability in 20-50% of cases to obtain the second specimen.[1, 2, 3]

Timely diagnosis of cystic fibrosis by newborn screening has always been critical, but increasingly so in recent years due to advances in CF treatment and the availability of preventive therapies that treat the underlying cause of the disease. Research shows that children with CF who receive care early in life have better nutrition and are healthier than those who are diagnosed later. Irreversible malnutrition due to pancreatic insufficiency and intestinal malabsorption occurs in many CF infants and can begin as early as two weeks of age.[4] Additionally, respiratory disease onset has been correlated with malnutrition as infection with *Pseudomonas aeruginosa* can occur early and lead to significant pulmonary disease within the first year of life.[5, 6] Therefore, any delay in the diagnosis exposes CF infants to both increased morbidity and mortality.

Moreover, babies of color with CF are more likely to be diagnosed later than white babies with CF. For babies born with CF from 2010 – 2018, median age of diagnosis was eight days later for babies of color compared to their white counterparts. [7] In Washington, median age of diagnosis was 19 days for babies with two variants detected by newborn screening, compared to 35 days for babies with one variant detected from 2019 – 2021.[8]

Babies of color are more likely to have one variant detected by newborn screening so racial and ethnic disparities related to timely diagnosis likely exist in Washington. This means that babies of color will especially benefit from the proposed newborn screening changes to improve timeliness.

Eliminating the second IRT analysis and improving timely diagnosis for babies with CF born in Washington will help children more quickly connect to specialized CF care and treatments. The CF Foundation and the undersigned clinicians from CF care centers throughout the state thank you for considering this important measure.

Sincerely,

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[8] Analysis of CF Foundation Patient Registry data by McColley SA and Martiniano SL.