



August 8, 2020

Dr. Margie Vandeven
Commissioner
Missouri Department of Elementary and Secondary Education
P.O. Box 480
Jefferson City, MO

Dear Dr. Vandeven,

On behalf of the 730 people in Missouri living with cystic fibrosis (CF), we write to urge the Missouri Department of Elementary and Secondary Education (DESE) to encourage all school districts in the state to offer remote learning as an option for the 2020-2021 academic year. Providing an alternative to in-person instruction will help safeguard students with CF and their families from exposure to COVID-19.

About cystic fibrosis and COVID-19

Cystic fibrosis is a life-threatening genetic disease that affects more than 30,000 people in the United States, including 350 children in Missouri. CF is a complex, multi-system disease that causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. Cystic fibrosis is both serious and progressive; lung damage caused by infection is irreversible and can have a lasting impact on length and quality of life. While great strides have been made in the treatment of the disease, CF continues to be a severe condition for which COVID-19 can pose serious health risks.

COVID-19 continues to present serious risk to Missouri residents, including those with CF. As of August 8, 2020, more than 160,000 people in the United States have died as a result of COVID-19, including 1,300 in Missouri.¹ Furthermore, over the last seven days, more than 7,000 cases in Missouri have been reported to the CDC—the 14th highest in the nation. As the number of cases increases and the risks continue, the CDC has recommended that Americans continue to reduce the risk of transmission of COVID-19 and protect those who are most vulnerable to infection.²

Remote learning as an option for the 2020-2021 academic year

As the DESE plans for the reopening of its K-12 schools for the 2020-2021 academic year, we urge you to encourage school districts in Missouri to extend remote learning as an accommodation for high-risk students and their families, including children with CF and their siblings. This request echoes the recommendations recently released by the American Academy of Pediatrics (AAP) that “special considerations and accommodations to account for the diversity of youth should be made, especially for our vulnerable populations, including those who are medically fragile.”³ According to the Centers for Disease Control and Prevention (CDC), those with CF may be at higher risk for severe illness from COVID-

¹ <https://www.cdc.gov/covid-data-tracker/>

² <https://www.cdc.gov/media/releases/2020/s0528-coronavirus-death-toll.html>

³ <https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/covid-19-planning-considerations-return-to-in-person-education-in-schools/>

19⁴ and the CDC's most recent guidance on school reopening recommends that schools have systems in place to support continuity or learning for students who need to stay home for either isolation or quarantine. This includes access to online learning, school meals, and other services.⁵

The Cystic Fibrosis Foundation believes that the decision to return to in-person learning should be made on a case-by-case basis and is best left to a child's family and their care team. As stated in our recently released guidance *Clinical Considerations: Returning to School*, care decisions should be made based on recommendations and the associated benefit-risk assessment of treatment options from CF care teams and the goals and circumstances of the patients and families they serve. Remote learning must be offered as an accommodation for children with CF and their siblings so that families can make the best choice for them during this difficult time.

Distance learning may be the safest instructional option to avoid exposure to COVID-19 infection. Instruction via the use of computers and reliable internet access, done synchronously or asynchronously, reduces physical exposure to others outside of the immediate household. Remote learning also allows students and adults who work in school settings to avoid exposure related to transportation, especially when commuting on school busses or public transport.

Additionally, some otherwise healthy students may live with a medically vulnerable person, including a sibling or parent with CF, for whom the potential risk of bringing the infection home from school may outweigh the benefits.

The Cystic Fibrosis Foundation urges you to advise local school districts to adopt remote learning as an option for people with CF and their families during the 2020-2021 academic year and we stand ready to serve as a resource to the DESE as you plan for the reopening of K-12 schools this fall. Please contact Lauren Ryan at lryan@cff.org or (301) 841-2632 if you would like to discuss this issue further.

Thank you for your attention to this important issue.

Sincerely,



Mary B. Dwight
Senior Vice President of Policy & Advocacy

⁴ <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html#copd>

⁵ <https://www.cdc.gov/coronavirus/2019-ncov/community/schools-childcare/prepare-safe-return.html>