



July 6, 2021

The Honorable Gavin Newsom  
Governor of California  
First Floor, State Capitol  
Sacramento, CA 95814

Dear Governor Newsom,

On behalf of the nearly 2,500 people with cystic fibrosis (CF) in California, we write to express our support for AB 382, which would extend the California Children’s Services Advisory Group (AG) for two years. The AG enables the Department of Health Care Services to have meaningful dialogue with stakeholders and work together on improvements to the California Children’s Services (CCS) program and implementation of the state’s patient-centered, quality care program, the “Whole Child Model”. CCS provides access to vital health services for the most vulnerable children living in the state, including those with CF, and the CF Foundation supports the continuation of the AG to facilitate continuous improvements to the program.

#### **About Cystic Fibrosis & the CF Foundation**

Cystic fibrosis is a life-threatening genetic disease that affects 30,000 children and adults 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. While great strides have been made in the treatment of the disease, the lives of young people with cystic fibrosis are still cut far too short; half of young adults with this disease still die before age 30.

The mission of the Cystic Fibrosis Foundation is to cure cystic fibrosis and to provide all people with CF the opportunity to lead long, fulfilling lives by funding research and drug development, partnering with the CF community, and advancing high-quality, specialized care. The Cystic Fibrosis Foundation accredits the more than 130 care centers in the United States—including 27 programs in California—and supports the development of CF clinical practice guidelines. Because cystic fibrosis requires targeted, specialized care and treatment, most people with CF receive care at one of these accredited CF care centers, which provide multidisciplinary care in accordance with systematically reviewed, data-driven clinical practice guidelines. Consistent care is a critical component of cystic fibrosis treatment, and any loss or gaps in health coverage may put the health of people with CF at risk.

#### **California Children’s Services Program and Advisory Group**

CCS is a crucial source of coverage for approximately 790 of the more than 1000 children living with CF in California and provides diagnostic and treatment services, medical case management, and hospital stays to children under age 21 with eligible medical conditions, such as cystic fibrosis. To be eligible for CCS a child must have or may have a medical problem that CCS covers; be a resident of California; and have a family income under \$40,000. CCS promotes an array of vital health care services for individuals with CF, including regular visits to accredited CF care centers, reimbursement for ancillary care provided by non-physician care team members, and vital therapies that form the core of CF treatment.

The CCS Advisory Group provides opportunities for stakeholders, including patients and their families, to provide feedback generally. Additionally, the AG acts as a unique forum where state administrators can share timely information and updates about the CCS program with the public, including providers and enrollees from across the state. Extending the AG will help ensure that children with cystic fibrosis continue to receive high quality, affordable health care through the CCS program.

We urge you to support AB 382. By supporting this bill, you will help ensure continued access to quality, specialty care for people with CF. The Cystic Fibrosis Foundation appreciates your attention to this important issue for the CF community in California.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

Mary B. Dwight  
Chief Policy & Advocacy Officer  
Senior Vice President, Policy & Advocacy  
Cystic Fibrosis Foundation

CC: The Honorable Sydney Kamlager