



March 20, 2023

The Honorable Bernie Sanders
Chair
HELP Committee
United States Senate
Washington, DC 20510

The Honorable Bill Cassidy, MD
Ranking Member
HELP Committee
United States Senate
Washington, DC 20510

Submitted electronically at HealthWorkforceComments@help.senate.gov

Dear Chairman Sanders and Ranking Member Cassidy:

The Cystic Fibrosis Foundation appreciates the opportunity to offer our insights regarding health care workforce shortages and potential solutions. The Cystic Fibrosis Foundation is a national organization dedicated to curing cystic fibrosis (CF). We invest in research and development of new CF therapies, advocate for access to care for people with CF, and fund and accredit a network of specialized CF care centers. We bring significant experience related to health care workforce issues as well as potential solutions for consideration.

Cystic fibrosis is a life-threatening genetic disease that affects close to 40,000 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. If left untreated, infections and exacerbations caused by CF can result in irreversible lung damage, and the associated symptoms of CF lead to early death, usually by respiratory failure.

In recent years, new treatments that address the underlying cause of CF have become available to approximately 90 percent of people with CF in the United States. As a result of those new therapies and through aggressive and continuously improving disease management, the median life expectancy for people with cystic fibrosis has risen steadily over the last few decades. This milestone reflects over 50 years of hard work by CF researchers and clinicians to improve CF treatments and develop evidence-based standards of care, as well as their commitment to supporting a lifetime of chronic care management.

The improvements in care—new treatments and aggressive disease management—and the resulting improvements in length and quality of life depend on an adequate, reliable, talented, and dedicated

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health care work force. Physicians, researchers, nurses, respiratory therapists, mental health providers, social workers, dietitians, pharmacists, and other health care professionals are essential members of the multidisciplinary CF care team. These specialized CF care teams can only function with a reliable health care workforce ready every day to meet the clinical needs of people with CF. Likewise, the development of new therapies relies on research teams that are stable and focused laser-like on discovery and development of new therapies.

The CF Foundation and people with CF are experiencing all facets of health care workforce challenges, including supply or recruitment, retention, and career advancement of health care professionals. The CF community, like the rest of the nation, is also confronting a problem of lack of diversity in the health care workforce. CF has historically been described as a Caucasian or white disease in literature – an inaccurate description since we know the disease can impact people of every racial and ethnic background. This misperception of CF continues to be widespread and can impact everything from diagnosis and access to information on the disease, to quality and delivery of medical treatment and overall health. For CF clinicians and researchers, the mischaracterization of CF as a disease that only impacts white people can also dissuade individuals from underrepresented backgrounds from entering the CF workforce.

CF Health Care Workforce Shortages in Context of National Trends

In her testimony before your committee, Sarah L. Szanton, RN, PhD, the Dean of Johns Hopkins University School of Nursing, identified the steps that she considers critical to improving the recruitment and retention of nurses. She described the process:

“To become a nurse, one needs to be able to imagine oneself as a nurse, to apply and be accepted by a nursing school, to have the resources to pay tuition, food, housing, and perhaps childcare while in the program. One needs to have dedicated time and space to learn. And then pass the nursing boards.

“For the school to be able to admit that student, it needs: enough faculty; adequate facilities; clinical settings in which to place nursing students for experience; and scholarships to offer.

“To stay in nursing, nurses need: supportive, safe work environments, a career ladder and, for some, the ability to return to school to develop the science behind prevention and care.”

Dr. Szanton describes persuasively the process for one to become and advance as a nurse, and her words resonated with us for their relevance to CF health care workforce challenges. Her description of the process for nurses to become nurses is analogous to becoming a member of a CF care center or CF research team. CF health care providers often say that they make the decision to do the work they do and keep doing the work they do because people with CF are inspiring and the rewards of caring for them are so rich. However, potential CF team members must imagine themselves in this role and then overcome the economic and other obstacles along their training path.

Here are some observations related to the CF health care workforce, consistent with Dr. Szanton’s observations and advice:

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Supply of Pulmonologists

A portion of pediatric pulmonary fellowship slots have in recent years gone unfilled, and this unfortunate trend will have an impact on the availability of pulmonologists to treat people with CF and lead multidisciplinary pediatric CF care teams. In 2022, only 41 percent of pediatric pulmonary fellow spots were filled by US applicants (73 percent including international applicants).¹ In 2019, the numbers were 34 percent and 54 percent, respectively. Of the pediatric pulmonology fellowships that were filled in 2020, the CF Foundation funded approximately 58 percent. The supply of pulmonologists in general has also been affected by the COVID-19 public health emergency (PHE), because pulmonologists have been on the frontlines of treating the most severely ill COVID-19 patients. Some have taken a break from medical practice or have left practice altogether.

As you know—and likely reinforced during your fact finding related to health care workforce shortages—the economics of medical practice influence decisions about residency and specialty practice. In the case of pulmonology, the economics of practice seem to be adversely affecting the supply of pediatric pulmonology fellows. And the COVID crisis has exacerbated troubling trends for quality CF care.

Economic Pressures

CF clinicians and physician scientists involved in CF research identify economic pressures from the beginning and throughout their training, pressures that influence whether they complete training or pursue their research careers in CF as opposed to choosing fields that provide better pay and an accelerated path toward freeing themselves of onerous student debt. Student loan repayment burdens and childcare expenses are two of many economic pressures that they experience.

We see the importance of programs like loan repayment and childcare assistance in data from CF research coordinators who manage clinical trials at CF care centers. Among research coordinators who participated in any CFF support program—which includes loan repayment (up to \$10,000 over three years) and childcare assistance (up to \$2,500 annually), along with coaching, mentoring, and certification programs—72 percent were still in their position after 3 years, compared to 44 percent who did not participate in a support program.

Career Advancement

From health care personnel in CF care centers offering multidisciplinary CF care, we increasingly hear about the economic pressures that they are experiencing and their concerns about a lack of career advancement both in terms of salary and in terms of growth and upward mobility in their position. They want reassurances that they can advance in their career within the CF care center, pursue additional training, and do all of that with some economic security. The focus on career advancement and a close connection with career satisfaction and retention has become more intense in recent years.

General Health Care Workforce Shortages

Approximately 40 percent of CF care centers—multidisciplinary care teams who care for people with CF—report staffing shortages. Specifically, 60 percent of CF programs report having under the guideline of 1-2 full time equivalent (FTE) per 200 patients in the social worker role, a role that has become increasingly more important with the psychosocial and mental health stressors of the pandemic. These shortages challenge the ability of the centers to provide the multidisciplinary care that people with CF

¹ National Resident Matching Program, “Results and Data: Specialties Matching Service, 2022 Appointment Year.” <https://www.nrmp.org/wp-content/uploads/2022/03/2022-SMS-Results-Data-FINAL.pdf>

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require and create additional stress for the professionals remaining on the team that can, in turn, lead to attrition.

Some of these existing issues were exacerbated during the COVID-19 pandemic and staffing levels still have not fully returned to pre-pandemic levels, as some staff left the health care workforce permanently. A survey of CF care teams during the early months of the pandemic found that 52 percent of care teams reported staff subject to furloughs, 51 percent reported hiring freezes, 34 percent reported decreases in salaries, and 10 percent reported layoffs.²

Lack of Diversity in CF Workforce

As discussed above, there is a lack of diversity in the CF workforce. There are historical reasons for this, related to the description of CF as a disease that affects only white individuals. This misperception creates an additional obstacle to diversifying the workforce.

In 2022, the CF Foundation launched a Summer Research Program, a targeted workforce development effort related to diversity, equity, and inclusion. This program provides grants to participating institutions with strong CF care and research programs to create summer research internship opportunities to cohorts that have been historically underrepresented in medicine and biomedical research. These opportunities will include research experiences in CF-focused research programs and introduce participants to multidisciplinary CF care teams. This effort is meant to expose students to a breadth of career options and help them develop and maintain an interest in a CF-related career, ultimately helping to build and grow a more diverse workforce.

Potential Legislative Solutions to Health Care Workforce Shortages

We have identified CF workforce issues in the context of the broader health care workforce crisis. We offer the following feedback on potential legislative solutions, with emphasis on those with relevance to CF workforce shortage issues:

Increase the number of health care professionals.

Update and bolster existing programs like the National Health Service Corps to meet current shortage issues. This is a critical pathway for shoring up the health care workforce and it requires an increased appropriation and should provide greater support for clinicians to meet current needs. The medical and nursing college leaders, health care economist, and health care system leader at the committee's recent hearing supported such overarching federal efforts to increase the number of health care professionals.

Enhance the use of technology to address workforce shortages.

Utilization of telehealth during the pandemic was critical to delivery of care when in-person care was challenging. Access to care via telehealth should be preserved as an option to assist in addressing workforce shortages. Telehealth can expand access to the CF care team, increase resources during critical events, shorten time to care, improve care coordination, and promotes patient-centered care. The use of telehealth reduces barriers to care for patients living in remote areas or unable to easily travel to appointments and it provides greater flexibility for providers to work from home or on less conventional schedules to balance childcare and other home responsibilities, allowing them to stay in the workforce. Remote patient monitoring should also be protected as a method for monitoring the health status of people with CF and others with chronic conditions. Preserving access to telehealth and

² Sawicki, GS, et al. Financial impacts of the COVID-19 pandemic on cystic fibrosis care: lessons for the future. [Journal of Cystic Fibrosis](#) 20 (30. December 2021: 16-20.

other remote services will require clarity about reimbursement and regulatory flexibility, including on issues of professional licensing.

Publicize private sector initiatives to support medical and research trainees.

A centralized database of private sector initiatives to provide financial assistance, including loan repayment assistance, to medical and research trainees should be developed and widely publicized. Federal support for the efforts of private entities should be considered, but in the meantime these private efforts should be publicized.

Encourage Interprofessional Education (IPE) training models.

The CF care centers provide multidisciplinary care to people with CF. Interprofessional Education (IPE) training models as recommended by the Institute of Medicine are a collaborative approach to develop health care students as future cross-discipline team members. The CF Foundation provides grant funding to CF care centers which includes funds to support continuing education of care team members. These funds allow care team members to attend the North American Cystic Fibrosis Conference each year which has discipline specific programming and provides continuing education credits, a cost that otherwise would come out of pocket or be limited by financial constraints of home institutions. There would be value in federal support for IPE, which would break down health care training and practice siloes.

Workforce diversity initiatives.

The committee received advice regarding utilization of the historically black colleges and universities (HBCU) medical schools to increase the diversity of the health care workforce. We commend those efforts to the committee. However, we also suggest that diversity efforts being advanced by private foundations and organizations be publicized and supported for their potential to increase diversity in specific specialties or practice areas. Even with a more diverse workforce, the CF Foundation will likely still need to undertake efforts to attract members of a diverse workforce to practice in CF.

Explore options to improve affordability of childcare.

Throughout conversations with CF care teams, the financial challenges of paying for health care degrees and licensing, coupled with the increasing cost of living were recurring themes. These issues have a direct impact on the health care workforce pipeline, as clinicians will not pursue these careers if it is not financially tenable. When asked about Foundation subsidies for childcare, individuals in the CF Childcare Support Program (CSP) stated, "juggling childcare while trying to build a research program is challenging and expensive." The CF CSP is only one program to help alleviate some of the financial challenges these research coordinators experience. At this time, the Foundation can only provide subsidies through this program for research coordinators, but with federal assistance, programs may be expanded to more care team members. In addition to augmenting scholarship and loan repayment programs, Congress should explore ways to make childcare more affordable to further alleviate some of the financial pressures on health care workers.

The CF Foundation appreciates the opportunity to offer recommendations to combat health care workforce shortages. We look forward to partnering with the Committee on these critical issues.

Sincerely,

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