MASSACHUSETTS GENERAL HOSPITAL
MassGeneral Hospital for Children
HARVARD MEDICAL SCHOOL

Testimony of Fiona S. Danaher, MD, MPH
Pediatrician, MGH Chelsea Pediatrics and MGH Child Protection Program
Co-Chair, MGH Immigrant Health Coalition
Instructor in Pediatrics, Harvard Medical School

On Behalf of Massachusetts General Hospital for Children

Before the U.S. House of Representatives
Committee on Oversight and Reform

"The Administration's Apparent Revocation of Medical Deferred Action for Critically Ill Children"

September 11, 2019

Chairman Cummings, Ranking Member Jordan, Subcommittee Chairman Raskin, and members of the Committee, thank you for the opportunity to testify before you today. I am Dr. Fiona Danaher, a pediatrician at Massachusetts General Hospital for Children, where much of my clinical work focuses on the care of children in immigrant families. I have come here today to express the profound concerns that I and my colleagues share over USCIS's potential termination of the medical deferred action program.

As you know, the medical deferred action program provides seriously ill children from immigrant families with the opportunity to preserve family unity while remaining in the United States for medical treatment. Our hospital cares for children who have benefited from the program, including a young child with a rare genetic condition that causes seizures and developmental challenges. In the country of origin, this child's condition is stigmatizing and deemed unworthy of care. The family was told the child would suffer from intractable seizures and die within a year. Refusing to accept that nothing could be done, the family left everything behind to seek a second opinion at a specialized Mass General clinic devoted to this genetic condition—one of only a handful of such clinics in the world. Thanks to the family's determination and the care of a dedicated clinical team, this child has lived a longer and much richer life, attending school and achieving some mobility and social skills. None of this would have been possible without the medical deferred action program. Now the child's status is due for renewal at a time when the program may arbitrarily end, jeopardizing much hard-won progress.

When pediatricians care for medically complex children, we often do so with bated breath. These children are, by definition, vulnerable. Whether they suffer from cancer, cystic fibrosis, muscular dystrophy, cerebral palsy, or one of any number of other diseases, they require care from a multidisciplinary team of specialists. Depending upon their underlying condition, an error as simple as a mis-dosed medication, a dislodged tracheostomy (breathing) tube, or a poorly covered sneeze could spell catastrophe. For many of these children, their health is so tenuous as to make travel unsafe, and their clinicians would hesitate to even transfer them to another hospital within the US, never mind overseas.

Should these children be forced to return to their home countries, their care may be impeded not only by stigma, as in our patient's case, but by lack of basic resources. Access to safe food and water is not a given in many parts of the world, and chronically ill children routinely die from malnutrition or infection as a result. Unreliable electrical grids threaten the health of children who depend upon interventions such as pumps, ventilators, or medications that spoil without consistent refrigeration. Particularly frail children can die from heat related complications for want of access to air conditioning. Severe air pollution in developing countries poses a dire hazard for children with underlying lung disease, and immunocompromised children are poorly equipped to handle exposure to endemic infectious diseases such as malaria, diarrhea, measles, and pneumonia.

Health care systems in many low middle-income countries are still in their nascence. Simply transporting an acutely ill child to a hospital can pose an insurmountable challenge in areas without ambulances or safe roads. Supply chains are inconsistent, so should the child make it to the hospital, the medications and equipment he or she needs may still prove unobtainable. Medically complex children can require access to oxygen, breathing or feeding tubes, special nutritional formulas, intravenous fluids, blood products, ventilators, dialysis, laboratory and radiology facilities—none of which are available in many resource limited settings, nor are the skilled personnel who would be needed to administer them. It is sadly not hyperbole to say that sending medically fragile children to such environments amounts to issuing them a death sentence. Adding insult to injury, such children could find themselves unable to access even the most rudimentary palliative care to ease the anxiety and physical pain of their passing.

Perhaps no intervention is more crucial to minimize the suffering of a severely ill child than maintaining the presence of a loving family member at the bedside. Terminating the medical deferred action program would leave some medically complex US citizen children struggling not only with the physical burden of their disease, but with the emotional trauma of forced separation from their immigrant parents. No child can be expected to heal under such circumstances. This is not just bad medicine; it is unconscionably inhumane.

The US Department of Health and Human Services building here in Washington, DC, bears an engraved quote from its namesake, Hubert H. Humphrey. It reads, "The moral test of government is how it treats those who are in the dawn of life, the children; those who are in the twilight of life, the aged; and those in the shadows of life, the sick, the needy and the handicapped." My colleagues at Mass General and I respectfully urge USCIS to embrace the moral imperative of permitting our young patients the opportunity to heal and to thrive, so that they may reach their full potential.