



September 17, 2019

Kenneth T. (Ken) Cuccinelli  
Acting Director  
U.S. Citizenship and Immigration Services  
20 Massachusetts Avenue, NW  
Washington, DC 20529

Dear Acting Director Cuccinelli:

On behalf of the 25 to 30 million Americans with one of the over 7,000 rare diseases, the National Organization for Rare Disorders (NORD) urges you to take immediate steps to reinstate adjudication of affirmative deferred action requests so that the lives of immigrants with rare diseases who are receiving needed medical care in the United States are not critically endangered by uncertainty and a lack of treatment. As a result of the recent policy change at the United States Citizenship and Immigration Services (USCIS), these individuals may face deportation, which could result in the deprivation of life-saving care.

Founded in 1983, NORD is the leading independent nonprofit organization representing the 25 to 30 million Americans with rare diseases. NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

Rare diseases are defined as diseases affecting fewer than 200,000 in the United States.<sup>1</sup> Even with all of the advances that the rare disease community has benefited from as a result of the Orphan Drug Act, over 90 percent of the approximately 7,000 known rare diseases still do not have a treatment indicated specifically for the disease that has been approved by the Food and Drug Administration (FDA).<sup>2</sup> Thus, there is still a great deal of research necessary to discover treatments and cures for these thousands of rare diseases. Many patients with rare diseases do not reside in the United States. Diagnosis and identification of rare disease patients can pose considerable challenges for entities in the United States seeking to conduct clinical trials on these small patient populations. It is in the collective interest of not only the rare disease community but of all Americans to ensure that if additional rare disease patients are needed, that patients and their caregivers who are willing and able to come to the United States to participate in a clinical trial do not face any barriers to doing so. Further, after having participated in the trial and advanced our collective scientific understanding of a disease, these individuals should be permitted to remain in the United States to continue receiving care without ever facing the threat of deportation if the treatment in question is not available in their country of origin.

Since the 1970s, USCIS has exercised prosecutorial discretion in the form of "deferred action" for individuals in exigent circumstances, including those with serious medical conditions and their caregivers. Under deferred action, individuals may remain in the United States without the threat of

---

<sup>1</sup> 21 C.F.R. § 316

<sup>2</sup> IQVIA. "Exclusivity, Pricing and Treated Populations." *Orphan Drugs in the United States*, December 18, 2018. [https://www.iqvia.com/-/media/iqvia/pdfs/institute-reports/orphan-drugs-in-the-united-states-exclusivity-pricing-and-treated-populations.pdf?\\_=1568137089860](https://www.iqvia.com/-/media/iqvia/pdfs/institute-reports/orphan-drugs-in-the-united-states-exclusivity-pricing-and-treated-populations.pdf?_=1568137089860).

immediate deportation. Through granting of deferred action, these immigrants with rare diseases and their caregivers have been able to remain in the United States and access life-sustaining, if not life-saving, care. During this time, many of these individuals also have been permitted to gain employment or enroll in school and have been able to live full lives.<sup>3</sup>

On August 7, 2019, USCIS stopped adjudicating requests for deferred action, retroactively and without any notice, to all of those living in the United States under the auspices of this long-standing process. In so doing, USCIS essentially pulled out the rug from under vulnerable families and individuals across the country. On September 2, 2019, USCIS announced that it would re-open cases for deferred action that were pending on August 7, 2019. However, it is uncertain if USCIS will adjudicate requests made after August 7, 2019. Instead, USCIS has stated that the granting of deferred action under these conditions will now be handled only by Immigration and Customs Enforcement (ICE). However, ICE generally does not consider requests of this nature until after immigration removal proceedings.<sup>4</sup>

Testimony from USCIS at a September 11, 2019, hearing before the House Oversight and Reform Subcommittee on Civil Rights and Civil Liberties added further confusion to the situation.<sup>5</sup> During the hearing, USCIS could not provide a date for resolution of the re-opened cases, clarity on the fate of future deferred action requests, or indication of a policy going forward. Consequently, the vast majority of those impacted by this sudden change in policy continue to live with uncertainty as to whether they can remain in the United States, further exacerbating the stress of living with a rare disease.<sup>6</sup>

The recent actions by USCIS have injected dangerous uncertainty and threatened the lives of rare disease patients who depend on care and treatments that, in many cases, can only be found in the United States. Given this uncertainty and the negative impact on the health of rare disease patients, we urge USCIS to immediately reinstate adjudication of affirmative deferred action requests for those living with rare diseases who are receiving needed medical care in the United States and their caregivers. Further, we urge USCIS to be transparent and seek public notice and comment for any policy changes. For questions regarding NORD or the above comments, please contact me at rsher@rarediseases.org or 202-588-5700.

Sincerely,



Rachel Sher Vice President of Policy and Regulatory Affairs

---

<sup>3</sup> Contreras, January. "Deferred Action: Recommendations to Improve Transparency and Consistency in the USCIS Process." Citizenship and Immigration Services Ombudsman. U.S. Department of Homeland Security, July 11, 2011. <https://www.dhs.gov/xlibrary/assets/cisomb-combined-dar.pdf>.

<sup>4</sup> "AILA - Featured Issue: USCIS's Elimination of Non-Military Deferred Action at Local USCIS Offices." American Immigration Lawyers Association, n.d. <https://www.aila.org/advo-media/issues/all/featured-issue-usciss-elimination-of-non-military>.

<sup>5</sup> House Committee on Oversight and Reform, Subcommittee on Civil Rights and Civil Liberties. September 11, 2019 hearing: "The Administration's Apparent Revocation of Medical Deferred Action for Critically Ill Children." <https://oversight.house.gov/legislation/hearings/the-administration-s-apparent-revocation-of-medical-deferred-action-for>.

<sup>6</sup> "USCIS Re-Opens Previously Pending Deferral Requests." USCIS, September 2, 2019. <https://www.uscis.gov/news/alerts/uscis-re-opens-previously-pending-deferral-requests>.