House Committee on Oversight and Reform
Subcommittee on Civil Rights and Civil Liberties

Hearing on:

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

Written Testimony

Submitted by Maria Isabel Bueso Barrera
Patient with a Rare Disease

I would like to thank Chairman Cummings, Ranking Member Jordan, members of the House Committee on Oversight and Reform, and the members of the Subcommittee on Civil Rights and Civil Liberties for this opportunity to speak before you and share my story.

My name is Maria Isabel Bueso Barrera. I'm 24 years old. I came to the United States from Guatemala when I was only seven years old, to participate in clinical trials that saved my life and have helped alleviate the suffering and extend the lives of thousands of people like me. I came here legally and have been a legal resident in this country for over 16 years. But on August 13, the U.S. Citizenship and Immigration Service sent a letter telling me and my family to leave this country by September 14, just a 33 day notice. While we were grateful to learn recently that our case would be re-opened, our future is still in question with no further communication or direction.

The medical treatment I need is not available in Guatemala. If I'm sent back, I will die.

I was born a seemingly normal and healthy baby, but when I was three weeks old, I began suffering from a series of health problems. No one knew the source of these problems until x-rays showed abnormalities in my bones. My pediatricians in Guatemala told my parents to contact a hospital in the United States to get an accurate diagnosis. My parents took me to Miami Children's Hospital in Florida and paid for doctor appointments and tests. The doctors in Miami confirmed that I was born with Maroteaux-Lamy Syndrome, also known as Mucopolysaccharidosis Type 6 (MPS-VI), which is believed to affect less than 2,000 people in the world. MPS-VI is a rare disorder caused by a gene abnormality. This mutation means that my body lacks an enzyme needed to break down certain sugar products. In a person with MPS-VI, a build-up of waste within the cells causes bone abnormalities, cardiac arrest, hydrocephalus, blindness, hearing loss, chronic pulmonary disease, and early death. My life expectancy was very short; doctors said I may not live to my teens.

The only treatment available for MPS-VI at the time was a bone marrow transplant. St. Jude's Hospital in Memphis, Tennessee, offered the transplant at no cost. We waited for five years in

Guatemala hoping for a transplant, but a perfect match donor was never found. Then, in 2001, my parents learned about an enzyme replacement therapy being tested in the United States on a three-year old boy named Ryan Dant for MPS I, another form of MPS similar to mine. My mother contacted the National MPS Society who put us in touch with Dr. Paul Harmatz at Children's Hospital and Research Center in Oakland. We were elated to learn that Dr Harmatz was also conducting clinical trials to evaluate the safety and effectiveness of an enzyme replacement therapy for patients with MPS-VI, and he desperately needed more patients willing to participate in this research.

Two years later I was selected to participate in Dr. Harmatz's trials and invited to come to the U.S. In 2003, my family and I came here with B-2 visas so that I could participate in the study sponsored by BioMarin Pharmaceutical Inc.

I was just seven years old when I started the first clinical trial. As a young child, it was not fun spending so much time in a hospital. I felt lonely being in a new place after leaving all that I knew -- my home, friends and extended family. There were so many blood draws, skin biopsies and MRI's, and I was scared of the needles. But I also understood that it was a chance for a brighter and healthier future and came to see it as an honor and a privilege. As I matured, it was rewarding to know that what I was going through was going to help a lot of people. I have continued participating in ongoing clinical trials over all these years and to this day, to help better the understanding of my disease for the next generation of children with MPS-VI.

The first study I participated in was successful and led to FDA approval of the drug Naglazyme to treat patients with MPS-VI. Thanks to this study, other children with MPS-VI in the United States now have a safe and effective treatment that will help them live longer and have a higher quality of life because this therapy relieves some of the worst of MPS-VI's disabling side effects, including problems with the heart, spine, bones and vision.

When the study ended, my parents learned that the medicine would not be available for distribution in Guatemala. So, as a family, we decided to relocate to California to make sure that I could continue receiving this life-saving treatment. Doctors told us that if we stopped the treatment, my condition would deteriorate quickly and I could die within months. In addition to MPS-VI, I suffer from paraplegia and I use a power wheelchair for mobility. I have a tracheotomy, and a VP shunt in my brain, making my health care even more complicated.

Still, the decision to relocate here permanently was hard on us. We were a middle class family in Guatemala. My parents left the comfort of a home and gave up jobs, careers, family and friends in order to be here with me. I missed my grandparents, aunts, uncles and cousins. It was also sad not having my friends around anymore. However, my parents helped me and my sister find normalcy as we made a life here in the United States. They rented a small apartment in Lafayette. We joined

a church and found love and friends in our local community. My father is a computer systems engineer and found a sponsor for an H-1B visa so that he could start working to provide for us.

In 2009, we petitioned for a change in status and we were granted deferred action for humanitarian reasons, so I could continue receiving the treatment I need to survive. We renewed this status every two years. I've now spent more than two-thirds of my life in this country, and I don't remember a lot about life in Guatemala. But this year, due to a change in policy, our request to extend our humanitarian visa was denied. Immigration Services no longer considers deferred action requests and the only firm direction we've been given is that USCIS wants us to leave the United States within 33 days of the date of the letter that was sent to my family on August 13, 2019. We understand and are grateful to hear this is now back under review, but have not received guidance to what lies ahead for our family.

If we return to Guatemala, I will not have access to the medical care and treatment I need and I will die.

But I want to live. I am a human being with hopes and dreams for my life.

Despite my physical challenges, I have worked hard to achieve my goals. In 2013, I supported a bill introduced by Assemblymember Marc Levine to establish February 28 as Rare Disease Day in California. I also testified in support of a bill to create the Rare Disease Advisory Council in California. I graduated Summa Cum Laude from California State University East Bay and was Director of the Associated Students for the Concord Campus. I established a scholarship to support students with physical and mental disabilities at CSUEB, and I was selected among 15 college and graduate students across the country to participate in a National Leadership Program with the organization Respect Ability to make a positive difference for people with disabilities. I now work as an advocate for people with rare diseases and have visited the California State Capitol in Sacramento and the U.S. Capitol in Washington DC for several years in that capacity. This summer, I was an intern at California Assemblymember Rob Bonta's District Office in Oakland, CA.

With the incredible support of my family, I have stayed positive and maintained hope through many struggles. I'm grateful for the opportunity this country has given me to receive medical treatment and to live much longer than expected. And I'm grateful for the humane immigration policies that have made my life here possible. And with that life, I want to make a difference for others.

I am so proud to have contributed to medical research that has helped ease the suffering and extend the lives of other children with my disorder. And I am honored to tell my story and be a voice for the many others whose lives are at risk if they are forced to leave this country.

And so I am asking Chairman Cummings, Ranking Member Jordan, the subcommittee, as well as President Trump, Senate Leader McConnell and House Speaker Pelosi, to please come together and right the wrong of this change of policy. This is not a partisan issue. This is a humanitarian issue. And our lives depend on it.

Thank you so much for your time and for considering my story.