

Truth in Testimony Disclosure Form

In accordance with Rule XI, clause 2(g)(5)*, of the *Rules of the House of Representatives*, witnesses are asked to disclose the following information. Please complete this form electronically by filling in the provided blanks.

Committee: Oversight and Reform

Subcommittee: Civil Rights and Civil Liberties

Hearing Date: September 11, 2019

Hearing Subject:

Termination by the Department of Homeland Security of non-military related deferred action requests

Witness Name: Jonathan Sanchez

Position/Title: Cystic Fibrosis Patient and Medical Deferred Action Applicant

Witness Type: Governmental Non-governmental

Are you representing yourself or an organization? Self Organization

If you are representing an organization, please list what entity or entities you are representing:

If you are a **non-governmental witness**, please list any federal grants or contracts (including subgrants or subcontracts) related to the hearing's subject matter that you or the organization(s) you represent at this hearing received in the current calendar year and previous two calendar years. Include the source and amount of each grant or contract. *If necessary, attach additional sheet(s) to provide more information.*

None

If you are a **non-governmental witness**, please list any contracts or payments originating with a foreign government and related to the hearing's subject matter that you or the organization(s) you represent at this hearing received in the current year and previous two calendar years. Include the amount and country of origin of each contract or payment. *If necessary, attach additional sheet(s) to provide more information.*

False Statements Certification

Knowingly providing material false information to this committee/subcommittee, or knowingly concealing material information from this committee/subcommittee, is a crime (18 U.S.C. § 1001). This form will be made part of the hearing record.

Jonathan Sanchez

Witness signature

9/10/19

Date

If you are a non-governmental witness, please ensure that you attach the following documents to this disclosure. Check both boxes to acknowledge that you have done so.

- Written statement of proposed testimony
- Curriculum vitae

*Rule XI, clause 2(g)(5), of the U.S. House of Representatives provides:

(5)(A) Each committee shall, to the greatest extent practicable, require witnesses who appear before it to submit in advance written statements of proposed testimony and to limit their initial presentations to the committee to brief summaries thereof.

(B) In the case of a witness appearing in a nongovernmental capacity, a written statement of proposed testimony shall include a curriculum vitae and a disclosure of any Federal grants or contracts, or contracts or payments originating with a foreign government, received during the current calendar year or either of the two previous calendar years by the witness or by an entity represented by the witness and related to the subject matter of the hearing.

(C) The disclosure referred to in subdivision (B) shall include—

- (i) the amount and source of each Federal grant (or subgrant thereof) or contract (or subcontract thereof) related to the subject matter of the hearing; and
- (ii) the amount and country of origin of any payment or contract related to the subject matter of the hearing originating with a foreign government.

(D) Such statements, with appropriate redactions to protect the privacy or security of the witness, shall be made publicly available in electronic form not later than one day after the witness appears.

Written Testimony of:

Jonathan Sanchez

Patient with Cystic Fibrosis and applicant for Medical Deferred Action

Submitted to the:

U.S. House of Representatives, Committee on Oversight and Reform
Subcommittee on Civil Rights and Civil Liberties

For a Hearing on:

*“The Administration’s Apparent Revocation of
Medical Deferred Action for Critically Ill Children”*

September 11, 2019

Dear Chairman Cummings, Ranking Member Jordan, and distinguished members of the subcommittee, it is an honor to speak before the Committee today. Thank you for the opportunity to share my story and to explain why medical deferred action is so important.

First, I would like to tell you about my life in Honduras, and then I would like to tell you how much it has changed since I came to the United States. Right now, I am 16 years old. I was born in Tegucigalpa, Honduras in 2003, and I lived there for the first 12 years of my life. When I was just three months old, my parents sent a sample of my blood to the Genzyme Corporation in Cambridge, Massachusetts, to see if I had Cystic Fibrosis (CF). The test results came back positive. It was a very scary day for my parents.

It was particularly frightening because three years before I was born, my parents had a daughter named Samantha. She was born with a problem with her intestines. My parents noticed that as she was growing, her health was declining. It seemed like she was sick, but they did not know what the problem was. My parents took her to two hospitals and unfortunately the doctors did not know what was wrong with her. They did not know what to do to make her better.

The sickness was making her body weaker and she could not resist anymore. My parents did a lot of research and thought she might have CF, so they sent a sample of her blood to get tested at Genzyme. Six months and two days after she was born, Samantha passed away. My parents were heartbroken. Then, one month after she died, they heard back from Genzyme and found out that she had CF. So, when they found out I had CF, they were terrified the same thing would happen to me.

They were right to be worried. Every day of my life in Honduras was a difficult and frightening ordeal. Every day was a struggle. I could not do anything that an average person could do. I could not walk too much. I could not run, jump, sprint, eat, or sleep the way other people do, and even going to the bathroom was complicated.

Back then I had tons of problems with my lungs, my pancreas, and with my digestive system. Every time I ate something with oil or fat, it gave me diarrhea. I constantly got extremely tired and I could not do any type of exercise. I could not ride a bike or use things like skateboards or roller skates like other kids did. I had tons of problems breathing and often got short of breath. When I could not breathe, this made me feel incredibly exhausted. On top of the physical struggles that I went through day-to-day, I also felt pretty bad mentally and emotionally.

I had all of these problems, but the doctors in Honduras could not help me. The doctors in Honduras were so ignorant that some of them thought my CF would disappear over time, while others thought I was exaggerating how I was feeling. They did not understand the disease or how it would affect my body, and they did not know what to do to treat it.

There is just no training around Cystic Fibrosis (CF) in Honduras, there are no specialists, and they do not have any teams to help address all of the problems that come from CF. They also do not have the medicine, machines, or resources to properly treat CF. Without these things, a person with CF will die very young.

When my parents found out that I had CF like my sister, they decided to investigate more and learn as much about CF as they could. They took me to see as many doctors as they could but the doctors felt threatened by their information about CF. They also tried to get me the proper medicines, but many of them were just not available in Honduras. They tried everything, but I kept getting sicker.

Twelve years after my parents found out that I had CF, they decided to try to get treatment for me in the USA. They had learned on some websites that there were hospitals and medical centers in the USA that could treat CF and extend people's lives. There was nothing else they could do for me in Honduras, so my parents wanted to see if there were any other treatment options here in America.

We traveled to USA on tourist visas and visited different hospitals trying to find the right treatment for me. Eventually we were sent to Boston Children's Hospital. The first visit I had there, I saw a lot of doctors on the same day. They were shocked and could not understand how I had lived so long without proper CF treatment. They ran a pulmonary function test and the result was that I had only 40-42 percent pulmonary function. They told my parents that my condition was very bad and that I was basically a dying body; that I had come to the USA literally dying.

After the first visit at Boston Children's, they sent me home with the essential CF medications, many of which I had not been able to get in Honduras, like pancreatic enzymes, medication for my stomach, and nebulizers. One month later they decided to admit me to the hospital for the first time. They gave me medicine and antibiotics through what they call a "pickline." They also had me start seeing a physical therapist and a chest therapist.

The first few months after I started getting the proper treatment, I felt tired, but not as incredibly tired as I had before. One week after I started the treatment, my doctors gave me another pulmonary function test and this time it was at 60-69 percent. Now my baseline is 90-97 percent. Once, I even got up to 107 percent, but that is rare and only happens once in a blue moon. I have been using a special medication called Orkambi that is not available in most other countries in the world, and this has really helped me.

CF requires daily treatment, so every day, I spend a total of between two and four hours using my chest percussion vest and nebulizers. I have to do this treatment in the morning, the afternoon and at night. I take a lot of medications every day, too. If I miss a day, this could be very bad for me. With CF, I also have to go to the hospital for regular check-ups, and sometimes if I have a respiratory infection, I have to be admitted to the hospital for a week or two.

Since I started getting treatment for CF, my physical and mental health has been better than before. Now with the proper treatment I received at BCH I can do lots of things regular people can do. About a year ago I went rock climbing. My primary nurse from the clinic saw me on the top of the rock wall and she said to my mother, "How did he get up there?" and she only gave a sign that meant, "I do not know." Being able to do things that other normal children can do has made me a lot happier. I have felt better about myself and have had more hope for the future.

However, since we got the letter denying our medical deferred action applications and telling us we may have to leave the country in 33 days or be deported, my parents and I have felt stressed, sad, scared, mad, and distressed. It is incredibly unfair to kick out sick kids who are in the hospital or at home taking treatments and who are just trying to have better opportunities to live.

The day our lawyers called to tell us the medical deferred action program had been canceled, my mom had her cell phone on speakerphone. I was in the same room and listened to the whole conversation. After the conversation ended, I started crying and said, "Mom, I don't want to die! I don't want to die! If I go back to Honduras, I won't survive."

After that I felt so tired, both emotionally and mentally. I could not sleep well and was waking up so many times during the night. I kept thinking, "What will happen tomorrow? Will I be alive, or will I be dead? What will happen to me?" I feel disappointed in the United States because it is supposed to be the county of opportunity. With this decision to end the medical deferred action program, they are denying me the opportunity to stay alive. When we got the news I felt like I was in Honduras again, where there is no justice or hope, where people do not care about the lives of other people.

On top of this, the government is treating me as if my life is not worth the same thing as other people's lives. It feels like the people who made this decision do not care what happens to me in the future. My mother and my father are so afraid for me that they have asked an American friend of ours if she will adopt me, if it comes to that, so that I can keep getting treatment here.

I feel that if the medical deferred action program is not reinstated it would not benefit this country to be known as they country that kicked out a lot of sick kids, one that decided to deport children even though they knew those kids would likely die. In my point of view, deporting me and other kids like me would be legal homicide. I do not feel that the rest of the world will approve of this. If this decision is not changed, I do not think the rest of the world will see this country as big anymore but will consider it small because they targeted weak people, and even worse, weak children.

As Members of Congress and especially Members who sit on the powerful Oversight Committee, I hope you will do everything in your power to fight for the reinstatement of this important, life-saving program. You have the power to order an investigation into why this decision was made and to tie funding to its reinstatement. If the program is reinstated, I will be able to breathe and I will be able to live. I will also be able to show the world the abilities I have and what I am capable of. Please help me and other the many other people who are in the same situation as me.

Thank you very much for your time.

Jonathan Sanchez

Biography

I am 16 years old. I was born in 2003 in Tegucigalpa, Honduras. I was born with Cystic Fibrosis. I received the official diagnosis when I was three months old. After arriving in the U.S. in March 2016 to seek medical treatment while here on a tourist visa, I was seen by a number of doctors at Boston Children's Hospital. They confirmed my diagnosis of Cystic Fibrosis and also diagnosed me with other medical issues: pre-diabetes, pancreatic insufficiency, and an enlarged heart, among other things. I'm going into the ninth grade and I enjoy learning about digital media. I like American football and I have become a Patriots fan.