

Statement of Diego Morris
“Connecting Patients to New and Potential Life Saving Treatments”
February 25, 2016

Good morning Mr. Chairman and members of the Committee. Senator Johnson, thank you for inviting me to testify. I am incredibly honored to be with you today.

I am grateful to have the opportunity to explain my story and tell you why I am dedicated to the Right to Try movement.

Four years ago I was a typical 11 year-old boy. I was playing two sports at the time, baseball and soccer. One morning I woke up with pain on the outside of my left knee. I thought it was just a typical sports injury. I continued to play in my games and did everything as usual for a few days. But the pain would not go away and it was causing me to limp. My mom took me to the pediatrician and thank goodness my doctor knew immediately that something was not right. She sent me to an orthopedic surgeon the following day for an X-ray. The doctor told my mom that he believed I had osteosarcoma, a rare type of bone tumor, just by looking at my X-ray.

The orthopedic surgeon sent us down to the lower floor for an MRI and my mom called my dad and asked him to come right over with my little brother, Mateo. My mom told me much later that she felt sick when she saw a technician running out the door. She knew he was running up to tell the surgeon of my results.

Everything happened quickly after that appointment. My parents consulted with many of their physician friends about what we should do next. My parents took the advice of our close family friends, he is a radiation oncologist and she is a pediatrician. They told my parents I needed to have a biopsy as soon as possible at a premier research institution.

Just three days after my trip to the pediatrician we were on our way to St. Jude Hospital in Memphis, Tennessee. We never stopped hoping I did not have cancer. After a long week of different types of tests and scans they performed a biopsy. We knew the surgeons would be looking at a quick type of analysis they perform in the operating room. They look at something called a frozen section during surgery to determine if a person's tumor is cancerous. If the surgeons determine it is cancer at that point, they go ahead and place a port in the patient's chest for treatment. When I had barely come out from anesthesia, I whispered to my parents - I asked them "do I have a port?" and they said "yes". The three of us cried and my life was never the same again.

After many conversations with physicians, we decided I should start chemotherapy treatment back home in Phoenix, Arizona. My parents came to the conclusion that if I would receive the exact same pre-surgery chemotherapy in Phoenix then I should be close to home, in my own bed as much as possible, surrounded by friends and family who love me. I received chemotherapy for ten weeks at Phoenix Children's Hospital before returning to St. Jude for limb salvage surgery. I am so grateful the surgeons were able to save my leg and completely remove the tumor. They inserted a significant titanium device in my leg which partially replaced my femur and my knee.

After surgery, the analysis of the tumor indicated that the necrosis, or the amount of the tumor killed off by the initial chemo, unfortunately was only fifty percent. The doctors were hoping to see at least eighty percent necrosis. This meant that I would need to have a very aggressive plan of treatment. I needed a total of twenty-one rounds of chemotherapy, with some of the strongest chemo drugs.

Thank goodness my parent's physician friends never stopped doing research on every available treatment for me. They told my parents about a drug called Mifamurtide, or MTP. MTP is an immune therapy drug that has improved survival rates for children with osteosarcoma. My parents were excited about the drug but quickly realized it had not been approved in the United States. MTP was available in so many countries all over the world, they were astonished it was not available in America. The trials for MTP had actually been started by physicians in the U.S.! My parents flew to Mexico City with our friend who is a pediatrician to see the results of MTP on their osteosarcoma patients. The doctors there showed them their findings and told my parents I was welcome in their hospital to obtain MTP.

The clock was ticking. In order to have MTP immune therapy I had to start it at the exact time I started my post-surgery chemotherapy - just ten weeks after undergoing significant surgery at St. Jude. My parents communicated with physicians in several countries and, after reviewing the facts of my case, every oncologist determined I fit the criteria and welcomed me at their hospital. My parents never gave up hope they could get MTP in America. They contacted our Congressman, the FDA, the drug manufacturer, and anyone they thought could help us find a way. They even spoke with the lead physicians for the US trials at MD Anderson and at Sloan Kettering. The doctor at Sloan Kettering explained MTP and answered all of my parents' questions. He told them there are no guarantees with MTP. My parents told him they weren't looking for guarantees - just hope. My dad asked the doctor one last question. He asked whether if (God forbid) the doctor's child or grandchild had osteosarcoma, would he take them out of the country in order to get MTP? He responded that he would indeed travel for MTP. Little did I know that we were about to make a very significant move in record time.

I will never forget my parents and their friends explaining to me and to my brother that we were going to London so I could have MTP treatment along with my chemotherapy. We were so upset with my parents at first but ultimately accepted the fact that this treatment might help save my life. Our entire family left our home in Phoenix, Arizona and moved 5,000 miles away. My dad commuted between Phoenix and London for nine months and my mom, brother and I lived with family in England. Throughout my MTP treatment and chemotherapy my parents continued to look for ways to get this treatment at home but it was just not possible.

My chemotherapy treatment was brutal and I was in the hospital more often than not. My dad was always exhausted and hated not being with us when I had to be rushed to the hospital for emergencies. My mom was exhausted too, going back and forth between the hospital and home to take care of me and my little brother. We were blessed to have relatives in England who insisted we stay with them. Many relatives were amazing to us, and showed us so much love and kindness.

But there is no place like home. I felt so isolated. I missed my friends, my home, my puppy and my school.

My family and I were very fortunate to have the resources to relocate to another country to get this potentially life saving treatment. Most people do not have that option. When my family and I returned to the United States we all agreed we would do anything to help other families not have to go through what we did to get treatment, or worse - not to have a promising treatment at all. So when the Goldwater Institute asked me to serve as the Honorary Chairman of the Right to Try campaign in Arizona I jumped at the opportunity. I am grateful to Darcy Olsen and the other people at Goldwater for giving me the chance to do something positive with my terrible experience. I am grateful to be alive and I am grateful to be here, with your esteemed Committee today.

Mr. Chairman, members of the Committee, thank you for giving me the opportunity to tell my story. I hope and pray we can make it possible for Americans to have easier, faster access to critical medical treatment. Please help us give Americans a better chance to save their own lives and those of their loved ones. No guarantees - just hope. Thank you very much.