Dear FDA,

I am a member of a family that is affected by Huntington’s disease. Even though the gene was discovered in 1993, over twenty years ago, there is still only one FDA-approved drug for Huntington’s disease, and that is simply unacceptable. Recently, we have seen clinical trials move outside the U.S. to other places like Europe or Canada. We have seen delay after delay.

The only explanation we can come up with is that the FDA must truly not understand Huntington’s disease. How could you? You aren’t sitting at home changing your loved one’s diapers, listening to your loved one choke all night, having to attend to injury after injury because of falls, watching your loved one not be able to talk, watching your loved one not be able to walk, watching your loved one end up on a feeding tube and even then be just skin and bones, watching your loved one suffer with anxiety and depression, watching your loved one suffer from suicide attempts, watching your loved one suffer from psychosis and paranoia and obsessive compulsive behaviors.

You don’t have to go to the doctor and have them look at you and say, “There is nothing we can do.” You don’t have to live with the excitement of finally hearing about a possible gene silencing therapy for HD and then have the disappointment of hearing that there will not be a clinical trial here in the U.S. after all.

Why are drug companies moving to other countries? The only answer we can think of is because of you. Why is promising research not able to get an IND to go into clinical trials? The only answer we can think of is because of you. Why do we continue hearing about delays? We know that is because of you.

You are the ones that are taking our hope away as we continue to see possible therapies and treatments not being able to get an IND. You have taken a job in which very important decisions must be made. You think you are protecting, but you are, in a sense, protecting us to death. We continue to live in fear that our children and grandchildren are going to have to endure the same pain and suffering that their parent has to endure because of you.

Can you even imagine growing up your whole life, seeing your mother or father go through horrific suffering, and learning that one day the same thing may happen to you? Can you imagine seeing your parent placed in a nursing home too far away to visit regularly, and realizing that one day the same thing may happen to you? Can you imagine finding out you have this disease and realizing that the children you’ve already had may one day suffer the same fate? Can you imagine watching your child begin to have physical and mental and cognitive problems in pre-school, only to learn the terrifying news that your child has Juvenile Huntington’s disease and is going to die before even having a chance to grow up?

We continue to hear things come from the FDA that show us you don’t understand our disease at all. You don’t understand how Huntington’s disease affects the quality of life for our loved ones and the quality of life for our families. You don’t understand that Huntington’s disease destroys families financially. You don’t understand that Huntington’s disease destroys marriages. You don’t understand that Huntington’s disease causes people to lose their children to child protective services. You don’t understand that Huntington’s disease causes caregivers to live in fear of violence from their loved ones. You don’t understand that Huntington’s disease steals every bit of quality of life from those who have it, leaving them totally dependent on caregivers for years and years and years. You don’t understand that Huntington’s disease destroys your home with broken dishes and glasses, broken chairs and sofas, broken cabinets and doors, broken toilet seats, holes in walls, and burns in furniture.

At the PDUFA meeting that our families attended two years ago, you said you understood that time is something we simply don’t have, but here we stand, two years later, in exactly the same place we were then. So you don’t understand.

We know that drug development is a business, and if drug companies are unable to receive INDs to move their research forward into a clinical trial, why will they keep investing money in research for Huntington’s disease? That would be a travesty, and that is blood on all of your hands.

Our loved ones are enduring more suffering than you could imagine. You have the luxury of not having to think about the future generations of your family being haunted by this horrific disease. We can *explain* this to you, but we can’t *understand* it for you.

Time is something we simply don’t have, and we deserve the right to try. We want stem cell research, and we want gene editing research, and we want gene silencing research. We want research for our children who suffer horribly from Juvenile Huntington’s disease. We want drugs that are being used off label to treat symptoms of Huntington’s and Juvenile Huntington’s disease to be approved for use with Huntington’s disease so that insurance will cover them. We need your help, and we need it NOW. How many more people will you allow to die before you allow research to move forward?