Good morning and thank you for having us here today. My name is Sue Burstein-Kahn and I am here to day representing not only ALS of Michigan – Lou Gehrig's Disease, but all of the pALS (persons with ALS) and their families throughout Michigan. I am also here as a surviving child of someone whose life was robbed by this devastating disease over 20 years ago – my Dad – Al Burstein.

There are many tragic diseases out there, but having personally experienced the havoc that ALS wreaks on patients and families, I can say with great confidence, that ALS is arguably the most devastating. It takes a generally healthy active person, in the prime of their life – between 40 and 65 - and robs them of mobility, their speech, their breathing, leaving them needing 14 hour a day, 7 day a week care, while their mind remains fully aware.

Here we are today, speaking, expressing our thoughts, our wants, our desires. Yet the majority victims of ALS lose their ability to do just this. Try forming words in your mouth when your tongue won't move. Thy swallowing your own saliva when your throat muscles won't cooperate. Try taking in a breath of air when your diaphragm won't expand. This is the life of our pALS in the latter stages of the disease.

We must investigate every avenue we have to stop devastating diseases like ALS. Embryonic stem cell research holds great promise for pALS in Michigan and around the country. We must give them the hope that they need to battle ALS.

When my dad was diagnosed my mother talked about getting him snake venom injections – because she had heard they might help. There was no science involved. There were no review committees. But there was desperation on her part because her husband had been told to go home and die. Today, our patients are traveling to countries in South America, to China, to undergo ESC procedures, and these are being done without the science, without the review committees, without the safety – because they need HOPE.

We must, as a compassionate society and a forward thinking State, make available to pALS and other who have been tragically struck with diseases like ALS, the best science possible – to help them live.

Thank you.