HTH-TEC
HEARING

SCR62

TESTIMONY

I strongly support SCR62.

Neurofibromatosis (NF) is the most prevalent genetic condition, and it does not affect individuals any differently based on gender, race, or ethnicity. For the most common type, NF1, a parent with NF has a 50% chance that his or her child will have NF, which represents half of the NF cases. The other half of NF cases occurs from a spontaneous genetic mutation. Together, NF affects 1 in 3,000 births.

NF1 is associated with a constellation of complications including bone abnormalities, learning disorders, and developmental delay. Mostly it causes tumors on nerve cells that can be in the skin causing disfigurement, eye causing blindness, spinal cord causing severe pain, and in the case of NF2 ear being a leading cause of deafness. NF can have a quite variable and unpredictable course, the effects begin in childhood, and there's no way to know what the future will hold.

There is no cure for NF, and there is not much industry interest in developing one. Government funding for research is critical to finding effective treatment and eventually a cure. The Department of Defense administered Congressionally Directed Medical Research Program (CDMRP) for Neurofibromatosis is the largest federal research program for NF.

The CDMRP was created under the leadership of the late Senator Daniel Inouye, who not only saw the importance of advancing the knowledge to help children afflicted with NF but also saw the military implications of better understanding nerve growth and generation. Senator Inouye was a champion of the CDMRP for NF who just last year secured funding despite widespread budget cuts.

I strongly support continued federal funding for NF research through the CDMRP for NF and renaming the CDMRP in honor of Senator Inouye. Thank you for the opportunity to provide testimony.