

Greetings - thank you to the committee for this chance to share some insight into the costs of ALS for those impacted by Genetic or Familial ALS & FTD. I am Jean Swidler chair of Genetic ALS & FTD: End the Legacy though I am speaking on my own behalf today. My great grandfather James in 1970 , my grandmother Lillian in 1990, my mother Kathy in 2019 and my aunt J in 2023 have died of ALS and they did and I do carry the c9orf72 repeat expansion.

First we must consider what the absence of grandparents may mean to people's lives. My grandmother died of ALS when I was 7 - many of my cousins never got to meet her and more do not remember her at all. My mother died of ALS before my daughter was born.

Next we must consider what the specter of a shortened life costs a person and their family. For the Hundreds of Thousands of Americans that carry the c9orf72 repeat expansion and other ALS genes we can predict our life will be on average only 64 years. Think about starting that down and the impact it may have on you or your spouse.. If your employer gets ahold of this information, imagine how that may impact your earning potential.

Finally lets think of brass tacks - the dollars and cents costs of care for ALS and FTD are large and like all of us, but perhaps at younger ages, we in inherited ALS families get hit with it coming and going. Coming is the time we miss from work and relationships to care for our parent or sibling with ALS and FTD, and going when our households need to source care for us as we suffer with ALS and FTD. My parents spent well over a hundred thousand on costs related to my mom's als even though she only survived 16 months after diagnosis.

On a haunting note we can think of one of the "upsides" of inherited ALS - reusing equipment! When my grandfather passed in 2015 (who had cared for my grandmother Lillian) my then presymptomatic Mom was sure to have the mothballed 20 foot wheelchair ramp taken over to our house a few blocks away for she was sure she would end up needing it. And she was right.