**Highlighted areas are text to customize and then remove the highlights.**

**If you need contact information for your members of Congress, go to** [**https://www.govtrack.us/congress/members**](https://www.govtrack.us/congress/members)**.**

(date)

Dear (Senator or Representative) \_\_\_\_\_\_\_\_\_:

I am writing as your constituent about several programs being considered before Congress right now and how they affect my family. My family (briefly tell how FX affects your family).

My family is part of the nearly 1 in 400 people in the US who carry a FX premutation or full mutation, meaning that **nearly 800,000 individuals in the US are directly impacted by FX**.

I am writing to discuss several issues before Congress wrapped up in both healthcare reform and the 2018 Budget. These three issues are vital to FX families like mine and have existing proposals to weaken them:

(You can personalize these to your family, such as, “Our son has FXS, so he has a pre-existing condition that will need medical coverage and care for the rest of his life.” Or “Medicaid’s Home and Community Based Services was critical because…”)

**Healthcare reform**. We all know the importance of health insurance coverage in the US. For everyone, it can be difficult, expensive, unruly, bureaucratic and confusing. For people with ongoing, preexisting conditions or life-long disabilities, it becomes even more critical and difficult. While we all agree on the need to improve the current system, well-intentioned people have sometimes cavernous differences on what the solutions looks like. One policy that should be universal, though, is the need to provide coverage for people with pre-existing conditions. Because FX is caused by an inherited gene mutation, it could be defined as a preexisting condition, even if disorders resulting from the mutation don’t manifest themselves for decades. **As you consider healthcare reform efforts, I ask that you insist on coverage for preexisting conditions.**

**Medicaid**. Medicaid is critical to FX families in a couple key areas. First, Medicaid’s Home and Community Based Services delivers critical early intervention to children with Fragile X syndrome. Depending on their state, some families are able to receive these services soon after they are needed, while others linger years and years on waiting lists. Reducing support for these programs negatively impacts the health and development of children with Fragile X syndrome, not only impacting their and their families’ lives, but potentially costing the taxpayers more money in the future. Investing in early intervention has been shown time and time again to be fiscally responsible policy.

As people with Fragile X syndrome grow into adulthood, many are not able to live on their own or be employed at a full-time job. Medicaid is the only option for health insurance. **Please don’t reduce funding to Medicaid.** It is literally a lifeline for many FX families.

**Supplemental Security Income and Social Security Disability Insurance**. SSI and SSDI are the federal programs to support those living with disabilities but not able to work, so it is clearly vital for many FX families and those living with FXS and FXTAS who are not capable of being gainfully employed. **Please don’t reduce funding and make program changes that negatively affect SSI or SSDI.**

I am available to discuss these issues further and think through how policy proposals will affect FX families. I can be reached at (phone number, address and email address).

Thank you for your time. I look forward to working with you to improve the lives of families living with FX.

Sincerely,

(your name)