**COPY/PASTE the following into your Senator’s online portal:**

Dear Senator\_\_\_\_\_\_:

I am reaching out on behalf of the International Rett Syndrome Foundation (formerly Rettsyndrome.org). Rett syndrome (RTT) is the most severe neurologic disorder to affect females in childhood, occurring in approximately 1 in 10,000 female births, and more rarely in males. RTT is characterized by a loss of acquired fine and gross motor skills and the development of neurological, cognitive, and autonomic dysfunction. Most children with RTT experience cardiac, respiratory, digestive, and muscular abnormalities, and are often unable to walk or talk. Further, many children with RTT develop scoliosis and seizures and require lifelong care, even as they live well into adulthood.

[ADD 3-4 SENTENCES ABOUT YOUR FAMILY’S EXPERIENCE WITH RETT.]

With no approved treatments, care providers can only rely on physical and occupational therapy, speech therapy, and seizure medications to manage the symptoms of disorder. As a rare disease, there are still no approved treatments available for those with RTT, and there is no cure.

As a family impacted by this disease, we request your support to include Rett syndrome as a research topic eligible for funding through the Peer Reviewed Medical Research Program (PRMRP) in the Fiscal Year 2023 Defense Appropriations bill. The current “explanatory statement” accompanying the Senate’s FY23 Defense Appropriations bill does *not* include Rett syndrome as a PRMRP topic. Thus, we respectfully request you to urge Chairman Tester (D-MT) and Ranking Senator Shelby (R-AL) of the Senate Defense Appropriations Subcommittee to add this topic to the final FY23 Defense funding bill as the Senate further considers this legislation. This listing will allow researchers to access funds to develop new treatments toward a cure for RTT.

Sincerely,

(Name and home address)