Secretary Robert F. Kennedy Jr.
U.S. Department of Health and Human Services
200 Independence Ave SW
Washington, D.C. 20201

Dr. Matthew Memoli, Acting Director
National Institutes of Health
9000 Rockville Pike
Bethesda, Md. 20892

Re: NIH Advisory Councils and Study Sections

Dear Secretary Kennedy and Acting Director Memoli:

On behalf of the Fragile X community, we would like to express our concerns that appropriated federal research funds are being blocked from reaching grantees, stopping imperative, curative research. We are especially concerned that the National Institutes of Health (NIH) Advisory Council meetings, previously scheduled for this past January and must disburse money for already peer reviewed grants, have not yet met. In addition, NIH is currently unable to post notices to the Federal Register, resulting in the cancellation of meetings for the review of NIH grant applications.

Mutations of the Fragile X (*FMR1*) gene result in behavioral, developmental, cognitive, reproductive, and potentially life-ending neurodegenerative conditions across generations in families and impact affected individuals from birth to death. Fragile X syndrome and associated conditions and disorders result from a single-gene mutation, which is the most common, known inherited cause of intellectual disabilities and autism. In fact, research has shown that the Fragile X protein (FMRP) regulates nearly one-half of the genes suspected of causing autism. Up to 100,000 Americans have Fragile X syndrome, and up to 1,500,000 Americans have a variation of the Fragile X mutation and as a result either have or are at risk for developing, one of the conditions associated with Fragile X and passing the gene mutation to their children. The known premutation issues are Fragile X¬ associated tremor/ataxia syndrome (FXTAS), a condition similar to Parkinson's, and Fragile X-associated primary ovarian insufficiency (FXPOI), which causes infertility and early menopause. As you can see, research into Fragile X does not just impact our community, but many of the American public and the conditions they live with and are seeking treatments and cures for.

Both the FRAXA Research Foundation and the National Fragile X Foundation strongly encourage the administration to remove the pause on Federal Register Notices and allow

the delayed NIH Councils and study sections to meet. This has enormous consequences for both ongoing studies, which may be irreparably harmed, and promising new research that cannot begin. Study sections and Councils are a vital and necessary step in funding research, ensuring that NIH-funded research is scientifically sound and rigorous and continuing successful ongoing studies.

Of particular importance is the funding of our Fragile X Centers within the Centers for Collaborative Research in Fragile X and FMR1-Associated Conditions. These Centers have shared the uncertainty regarding whether their research will be funded or not, despite their grant application receiving an outstanding score from a scientific panel of peers, has created and will continue to create challenges in staffing and progress for Fragile X.

On behalf of the professionals who have dedicated their careers to Fragile X research and the community of families they serve, we appreciate the administration's interest in strengthening the NIH and look forward to working with you to advance all biomedical research and specifically Fragile X research.

If you have any questions, please contact the individuals listed below. Thank you for your time and attention to our concerns.

Sincerely,

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