The Honorable Robert F. Kennedy, Jr.

Secretary of Health and Human Services
U.S. Department of Health & Human Services
200 Independence Avenue SW
Washington, D.C. 20201

Dear Secretary Kennedy,

On behalf of the millions of Americans living with rare diseases and the thousands of families who have signed this letter, we urge you to continue and expand vital funding for rare disease research.

More than 30 million Americans—nearly 1 in 10—are affected by a rare disease, and for many, there are no approved treatments or cures. This is certainly true for rare pediatric autoimmune diseases, where the Cure JM Foundation has been a research leader and partner with the NIH over our 22-year history.

Federally assisted research has been a lifeline for rare disease patients, accelerating breakthroughs in gene therapy, precision medicine, and innovative treatments that offer hope where none previously existed. For many rare or orphan diseases, breakthrough research is largely funded through private donations to non-profit organizations and not by the Federal government. However, we cannot stress enough the critical importance of research collaboration with the NIH and FDA. These organizations bring unparalleled medical expertise to our common mission of finding better treatments and cures.

For families of the Cure JM Foundation, NIH partnerships have been critical in the identification of potential and proven new therapies. Discoveries made possible by NIH often provide the scientific evidence that pharmaceutical and biotech companies need to derisk private industry investment in new therapies for rare diseases. Among rare childhood diseases such as juvenile myositis or pediatric lupus, NIH leadership has quite simply been life-saving.

As Secretary of Health and Human Services, you have the power to champion the rare disease community by ensuring that critical research focus and partnerships remain a priority among the goals of your administration. The NIH, the FDA, and other key agencies rely on continued federal investment to drive scientific discoveries that can and already has

improved the lives of millions of Americans and others around the world who live with rare diseases.

The thousands of families who have signed this letter are not just names on a page—they are parents, grandparents, children, caregivers, and patients fighting every day for better treatments, for more research, and most importantly for the hope you can give them. We stand together in urging you to prioritize rare disease research in your leadership at HHS.

The rare disease community is resilient, but we cannot do this alone. We need your leadership and commitment to ensure that no patient is left behind simply because their disease is rare.

Thank you for your thoughtful consideration of the rare disease communities as you move to affect change at HHS. We look forward to continued research partnerships that assure that all families living with rare diseases will celebrate the ongoing progress toward treatments and cures that our government has championed.

Sincerely,

Jim Minow

Executive Director, Cure JM Foundation
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On behalf of the families and individuals who have signed on to this letter to date