### **(Your Name)**

[Your Address]

 [City, State, ZIP]

 [Email]

 [Phone Number]

 [Date]

**The Honorable [Representative/Senator’s Name]**

 ENTER THIS FOR **Subject: Urgent Legislative Action Needed to Protect NIH Funding for Ultra-Rare Disease Research**

Dear [Representative/Senator] [Last Name],

I am writing to express my deep concern regarding the recent and proposed budget cuts to the National Institutes of Health (NIH) and the devastating impact these reductions will have on research for ultra-rare diseases, including **galactosemia**. As a legislative advocate and Grandparent of a child with this ultra-rare genetic disorder, I have witnessed firsthand how critical NIH-funded research is to advancing potential treatments and improving patient outcomes.

**Galactosemia is a ultra rare metabolic disorder with no FDA-approved treatments.** Patients must follow a strict, lifelong dietary restriction, yet they still suffer from severe complications, including cognitive impairments, speech delays, osteoporosis, and ovarian insufficiency. The lack of research funding has already hindered progress, and further NIH budget cuts will **halt critical studies, delay scientific breakthroughs, and leave families like mine without hope. Dr Judy Judith L. Fridovich-Keil PhD from Emory University has reached out saying her research for galactosemia is in jeopardy due to this budget cut. She is one of the very few researching Galactosemia. We need to protect vulnerable ultra rare disease from these budget cuts.**

 **Legislative Ask:**

I urge you to **prioritize robust NIH funding** in the upcoming appropriations bill, specifically by:

1. **Restoring and increasing NIH’s budget allocation** to protect research for ultra-rare diseases, ensuring that programs like the NIH Office of Rare Diseases Research (ORDR) and National Center for Advancing Translational Sciences (NCATS) continue their essential work.
2. **Supporting and co-sponsoring legislation** that strengthens federal investment in ultra-rare disease research, such as the **Cures 2.0 Act** and additional funding allocations for NCATS to expand clinical trials.
3. **Advocating for dedicated funding streams within the NIH** to directly support ultra-rare disease research, including a specific NIH grant mechanism for diseases with fewer than 5,000 cases in the U.S.

Without dedicated funding, ultra-rare diseases like galactosemia will remain neglected, leaving thousands of patients and families without treatment options. **I respectfully request a meeting with your office** to discuss how we can work together to protect NIH funding and accelerate research for galactosemia and other rare diseases.

I appreciate your time and commitment to advancing healthcare for all Americans. Please feel free to contact me at [your email] or [your phone number] to schedule a conversation. I look forward to your response.

Sincerely,

 **[Your Name]**

 [Your Title/Organization, if applicable]

 [Your Contact Information]