

CURED

Campaign Urging Research for Eosinophilic Disease



FOR IMMEDIATE RELEASE

April 16, 2025

NIH Decision Devastates Two Rare Disease Consortia — Advocates Urge Immediate Attention

Washington, D.C. — In an unprecedented move, the National Institutes of Health (NIH) has withdrawn resubmitted funding applications from two federally recognized Rare Disease Clinical Research Consortia—the Frontiers in Congenital Disorders of Glycosylation Consortium (FCDGC) and the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR)—over a minor paperwork technicality. This decision, made just days before the final scientific review, has sent shockwaves through the rare disease community and threatens decades of progress in research, diagnostics, and treatment development for thousands of vulnerable children and their families.

“This isn’t just a bureaucratic setback—this is a targeted blow to the heart of rare disease research infrastructure,” said Andrea Miller, JD, MHA, Executive Director of CDG CARE. “Our families already live on the edge of medical uncertainty. To have hope taken away due to an easily correctable clerical error is unconscionable.”

“We are stunned,” added Elyn Kodroff, President of CURED. “Our researchers, families, and patients—many of whom depend on NIH-supported studies—have been left in limbo. We urge the public and press to help us bring attention to this injustice before it sets a harmful precedent.”

Not Based on Scientific Merit

Both consortia previously secured NIH funding after thorough scientific reviews. Their current applications were strengthened with updated data, broader community engagement, and expanded outreach, yet were disqualified over the absence of a “Foreign Justification Document.” Historically, this document has been submitted during the “Just-in-Time” phase following scientific review, making its citation as grounds for rejection unprecedented.

Internal NIH sources have expressed frustration, confirming that the decision stems from higher-level directives. Appeals at multiple levels have been denied, leaving longstanding research teams and patient communities without recourse. The enforcement of this administrative shift threatens critical clinical research infrastructure, including multi-site studies, patient registries, and natural history initiatives vital to rare disease families worldwide.

Advocates Urge Immediate Action

CDG CARE and CURED are calling on Congress, the Rare Disease Congressional Caucus, and the public to demand reinstatement of the applications before the next NIH review cycle on April 22, 2025. Advocates have flooded congressional offices with emails and calls to leaders, including Reps. Gus Bilirakis, Doris Matsui, and Sens. Roger Wicker and Amy Klobuchar, co-chairs of the Rare Disease Congressional Caucus.

“We’re mobilizing every resource—alerting media, contacting committees—but we need the public to care,” said Miller. “If this can happen to us, it can happen to any rare disease group.”

Interview Opportunities

Representatives from CDG CARE and CURED, alongside affected families, clinicians, and researchers, are available for interviews to discuss:

- The significance of these NIH-funded consortia.
- The withdrawal and its repercussions.
- The broader implications for NIH policies on medical research access.

For interview requests or additional information:

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About CDG CARE

CDG CARE is the leading U.S. advocacy organization supporting families impacted by Congenital Disorders of Glycosylation (CDG), a group of over 200 rare inherited conditions affecting multiple systems. CDG CARE funds research and provides family support to improve lives.

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