Undiagnosed Diseases Network Foundation

Undiagnosed Diseases Network Foundation
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The Honorable Representative Marilyn Strickland
1724 Longworth House Office Building 1724
Washington, DC 20515

Re: Statement in Support of the HEARD Act on Behalf of the Undiagnosed Diseases Network Foundation (UDNF)

Dear Congresswoman Marilyn Strickland,

On behalf of the Undiagnosed Diseases Network Foundation (UDNF) and the millions of Americans living with rare and undiagnosed diseases, we strongly urge you to support and advance the Health Equity and Rare Disease (HEARD) Act. This critical legislation is a long-overdue step toward ensuring that no patient—regardless of how rare their condition—goes without the answers, care, and treatment they deserve.

For the 30 million Americans affected by a rare disease, access to timely diagnosis, treatment, and research remains a significant challenge. Many of these individuals, particularly those in underserved and underrepresented communities, experience years of misdiagnoses, limited treatment options, and high healthcare costs—all while their conditions worsen. The HEARD Act directly addresses these disparities by:

- Developing a comprehensive federal plan to improve rare disease diagnosis, treatment, and research outcomes.
- Providing federal grant funding to expand patient services, research initiatives, and community-based support programs.
- Investing in the rare disease workforce through scholarships and loan repayment programs to encourage more healthcare professionals to specialize in rare conditions.

- Enhancing clinical trials, data collection, and early screening efforts to improve patient outcomes and accelerate medical discoveries.
- Supporting Native and Tribal health centers in conducting rare disease research and expanding care to historically underserved populations.

Too many families are left without answers for years, bouncing between doctors who lack the resources or expertise to diagnose their condition. Over 25% of rare disease patients wait seven years or longer for an accurate diagnosis, and only 5% of rare diseases have an FDA-approved treatment. This delay is more than an inconvenience—it can mean the difference between life and death. The HEARD Act will provide the federal commitment and resources needed to bridge this gap, ensuring that patients are not left in the dark simply because their disease is considered rare.

For many families, this bill represents the difference between hope and despair—between getting a diagnosis and continuing to live in uncertainty. The HEARD Act is more than just legislation; it is a promise that our healthcare system will no longer ignore the rare disease community.

We urge Congress to pass the HEARD Act and stand with the millions of Americans fighting rare and undiagnosed diseases. Their lives depend on it.

Sincerely,
Carrie Borrello
Undiagnosed Diseases Network Foundation (UDNF)