

WHY THE ALLIANCE EXISTS

HMERF changes lives. But it does not define them.

Around the world, individuals and families face a progressive disease with no approved treatment.

The Alliance unites patients, families, clinicians, researchers, and supporters around one shared mission:

TO ACCELERATE THE DEVELOPMENT OF THE FIRST TREATMENT FOR HMERF

OUR JOURNEY

- **2004** A family loses a loved one to HMERF.
- **2016** Another generation receives the same diagnosis.
- **2019** The search for answers becomes a mission.
- **2020** A nonprofit research organization is established.
- **2025** The Alliance expands to unite the global community.

The Alliance exists to serve every individual and family affected by HMERF.
NO FAMILY SHOULD FACE HMERF ALONE.



FROM DISCOVERY TO TREATMENT

A science-driven journey. A future filled with hope.

WHAT IS HMERF?

Hereditary Myopathy with Early Respiratory Failure

HMERF is a rare, genetic muscle disease caused by mutations in the TTN gene. It leads to progressive muscle weakness and respiratory failure, often requiring wheelchair use and ventilator support.



RESPIRATORY INVOLVEMENT

Leads to weakened breathing muscles and respiratory failure.



PROGRESSIVE WEAKNESS

Affects limb, core, and respiratory muscles over time.



MOBILITY IMPACT

Many individuals use a wheelchair as the disease progresses.



POTENTIAL CARDIAC INVOLVEMENT

Some individuals may experience heart complications.

NO APPROVED TREATMENT. NO CURE.

Research is our only path forward.



Every donation helps move this journey forward.

Research happens because people choose to invest in hope.

INVEST IN THE FUTURE OF HMERF

Your support fuels real progress toward the first treatment for HMERF.

1

FUND RESEARCH

Support laboratory and preclinical research.

2

BUILD THE GLOBAL COMMUNITY

Connect patients, families, clinicians, and researchers.

3

CONNECT PATIENTS & FAMILIES

Provide resources, support, and community.

4

STRENGTHEN THE REGISTRY

Accelerate research and clinical-trial readiness.

5

ACCELERATE DEVELOPMENT

Move promising therapies to clinical trials.

6

ADVANCE COLLABORATION

Partner with leading scientists and clinicians.



BECOME A RESEARCH PARTNER

Monthly gifts power the science that can change lives.

\$25 / MONTH

Serving patients, families, researchers, and clinicians worldwide.