FSHD SOCIETY

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What is FSHD?

Facioscapulohumeral Muscular Dystrophy (FSHD) is a genetic, progressive muscle-wasting disease affecting approximately 1 in 8,000 people, or an estimated 43,000 Americans. FSHD can affect any gender, race, and ethnicity, and onset can happen at any age. Many FSHD patients start to experience symptoms in their teens or early 20's, but about 10% of people develop symptoms before age 10. Typically beginning with the loss of muscles in the face (facio), shoulders (scapula), and upper arms (humerus), FSHD can spread to any muscle. Around 20% of people will use a wheelchair by age 50. For the 96% of patients who experience shoulder and upper arm weakness, there are limited choices for assistive devices to aid in upper body mobility. Over 70% of patients experience debilitating pain and fatigue, which can significantly impact daily life and independence. The condition is primarily inherited and can impact families across multiple generations, yet about 30% of cases arise in families with no prior history.

FSHD is **relentless**. Recent research has shown that every day without a treatment is muscle lost. Even when the disease progression appears to stabilize, the cell damage is ongoing and can result in sudden changes in a patient's functional abilities. MRI studies demonstrate that muscle cells are dying steadily over time, putting strain on compensatory systems until the body gives out and the patient experiences a sudden and devastating loss of function. There is a constant undercurrent of fear about what ability will disappear overnight. Injuries that would be considered minor to most people are catastrophic when you can't recover from muscle atrophy. **There is not yet any approved treatment**. This community has no time to wait.

Impact on Daily Life

Patients from the FSHD community have been unanimous and clear that what they want is an intervention that slows or stops their disease progression. Minor changes are significant; for example: A treatment that reduces fatigue enough to allow a patient to type for half an hour longer would allow a person to remain at their job or in school without special accommodation. Relating to hygiene and tasks of daily living, an additional 5% range of motion may make the difference for someone who could bathe and groom themselves, rather than requiring assistance from family or a caregiver. The strength to lift an extra pound could be all it takes for a person to be able to do their own grocery shopping, rather than to pay extra for a delivery service. It is these small differences in strength, endurance, and mobility that have huge impact on a person's independence and quality of life.

Pain and fatigue are ubiquitous secondary symptoms of FSHD. Sometimes these facets of the disease have the most significant impact on a patient's daily life, and any intervention that addresses these things can make as big of a functional difference as interrupting the underlying disease process.

Unlike some other myopathies, FSHD has no cognitive impact, even in its most severe forms. People who are suffering FSHD-related physical disability are still engaged in all forms of intellectual work. FSHD patients are doctors, lawyers, accountants, and senior strategists. FSHD has a real economic cost to our country, when patients are physically unable to work even though they are still highly valuable to their fields.

Military Relevance

Understanding muscle-wasting disease, and the drugs being developed to treat it, is highly relevant to military readiness:

-Treatment Approaches:

Multiple treatments being developed in FSHD take a “platform approach”, where one technology is being utilized (with slight tweaks to the formulation) to treat multiple forms of muscular dystrophy, thus extending the application beyond just one rare condition. In these “dual usage” scenarios, advancement in the treatment of FSHD represents success in multiple disease spaces, impacting a much larger percentage of the military community.

Another approach to treating FSHD involves muscle regeneration. In this instance, drugs are being developed to overcome disease processes rather than intercept them, allowing muscle to rebuild and preserve function over time. Successfully repairing muscle on a cellular level has broad application across disease processes and traumatic injury. A proof of concept in FSHD has the potential to change the field of muscle health overall.

-Examples of Impact to the Warfighter:

G.L. spent the majority of his career as a Navy helicopter pilot. Due to the fatigue caused by his FSHD, and the increasing difficulty he had reaching above shoulder height, he retired early from his military career. His family did not have a history of the disease, so it was difficult for him to get diagnosed. He intended to serve for much longer, but was so worried about his health, he made the difficult decision to return to civilian life.

FSHD runs in R.H.’s family, and his mother and several siblings are affected – as are many extended family members. His father was a high-ranking member of the military but had to leave service in order to be more present at home and care for his multiple affected family members. Although he did not have FSHD himself, the family inheritance of FSHD impacted his length of service.

Summary

FSHD is an insidious disease, affecting Americans of all ages, genders, and backgrounds. The US military has likely lost hundreds or thousands of top-tier service members to the impacts of the disease, both as patients and as family caregivers. Treatments are being developed, but they cannot come fast enough for the families who live with FSHD. Additionally, there is still more to learn about how the disease process works, and more information is critical at this moment in development. With so much momentum already pushing basic, translational, and clinical trial research forward right now, investment in FSHD research has a timely and critical impact. Americans and military families are suffering the many devastations of this cruel disease. We cannot afford to lose more time. For families living with FSHD, time is muscle.