

Leading the Way



About the FSH Society

Founded in 1991 by patients, the FSH Society is the world's largest grassroots network of facioscapulohumeral muscular dystrophy (FSHD) patients, their families, and research activists.

What Is FSHD?

Facioscapulohumeral muscular dystrophy, or FSHD, is a genetic disorder that causes weakening of the skeletal muscles. Typically beginning in early adolescence with the loss of muscle strength in the face (facio), shoulders (scapula), upper arms (humerus), legs or core, FSHD can spread to any muscle. Ten percent of patients have onset of symptoms before age 10. About 20 percent will need a wheelchair by age 50. Over 70 percent experience debilitating pain and fatigue. There is no effective treatment or cure—but there is hope.

Who Is Affected?

An estimated one in 8,000 individuals, or 870,000 people worldwide. The condition is inherited and can affect many family members across generations. Some 30 percent of cases arise in families with no prior history. No individual or family is immune.

What Is the FSH Society?

The FSH Society helps people through education and outreach; funds scientific and medical research; and advocates for increased government and industry investment in FSHD.

We Have Transformed the Landscape

Patients once had no place to turn for help. There was virtually no research on FSHD. The FSH Society raised funds that launched many areas of FSHD research. We helped to write the MD-CARE Act (2001), which led to the creation of the NIH-funded Wellstone Centers for FSHD research. The Society has invested over \$6 million in research, contributing to the discovery of the genetic cause of FSHD and igniting interest by more than a dozen biotech companies in developing treatments.

We Are Taking Action To:

- Identify biological mechanisms of the disease;
- build critical infrastructure to accelerate research;
- improve patient care nationwide;
- pave the way to clinical trials.

"We believe there will be a cure one day for our son Noah, and we know the FSH Society will play a huge role in finding it."

— Kristen and Dan Linsky

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www.fshsociety.org

- Join the FSH Society.
- Get educated. *Knowledge is power.*
- Get active! Connect with local members.
- Volunteer for research.
- Donate! Without you, we can't win this fight.

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We have earned your trust. In 2016, the FSH Society earned its ninth consecutive 4-Star award from Charity Navigator, placing us among the highest-performing U.S. charities.

