Help Advance Science, Treatment and Care

You Can Contribute to the Fight Against Kennedy's Disease

The Global KD/SBMA Patient Registry is one of the most important ways patients and carriers can contribute to advancing science and care.

JOIN PATIENT REGISTRY

Secure and Confidential

Be Part of the World's Largest, Most Comprehensive KD/ SBMA Registry

CoRDS is the global patient registry for Kennedy's Disease/SBMA. The registry is compliant with U.S. federal laws and the European Union's General Data Protection Regulation.

Kennedy's Disease Association

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Kennedy's Disease Association

The mission of the Kennedy's Disease Association is to inform, support, educate, fund research and find a cure for Kennedy's Disease.

www.kennedysdisease.org

Kennedy's Disease Association

The Kennedy's Disease Association (KDA) is a nonprofit organization dedicated to:

Supporting individuals and families living with KD/SBMA

Promoting awareness and education

Funding research and connecting patients to studies

Building a global community

Whether you've just received a diagnosis or are looking to connect with others, the KDA is here to help.

What is Kennedy's Disease?

Kennedy's Disease (KD), also known as Spinal and Bulbar Muscular Atrophy (SBMA), is a rare, inherited neuromuscular disorder that primarily affects males.

Genetics and Inheritance

Kennedy's Disease is caused by a mutation in the androgen receptor (AR) gene on the X chromosome. This mutation involves an abnormal repetition of a DNA sequence (also known as CAG trinucleotide expansion) in the gene.

The defective receptor accumulates within nerve and muscle cells causing them not to function correctly.

Living with Kennedy's Disease

Kennedy's Disease affects individuals differently, and severity and progression can vary widely. Symptoms often begin between the ages of 30 and 50, although onset can occur anytime between 18 and 60.

Females who inherit the gene mutation from their mothers are considered *carriers* and have a 50% chance of passing the gene on to each child. Females who inherit the gene mutation from their fathers are considered *obligate carriers*, meaning they will carry the gene mutation with 100% certainty. Carriers may experience symptoms. Diagnosis is confirmed by genetic testing.

There is no effective treatment or cure, however many individuals live active, fulfilling lives with the right care and support. Supportive therapies, lifestyle adaptations, and staying connected to the KDA community can make a significant difference.

Common Symptoms

Early to top progression:

- Cramps, twitching, tremors
- Breast enlargement (Gynecomastia) and reduced fertility in males
- Muscle weakness and wasting, especially in the arms and legs
- Difficulty speaking or swallowing
- Numbness or tingling in hands and feet
- Breathing difficulties (later stages)

Managing Symptoms

- A team-based care approach involving neurologists and other specialists
- Physical and occupational therapy
- Speech and swallowing support
- Endocrine care for hormone-related symptoms
- Assistive technologies and mobility aids

Become a Member of the KDA COMMUNITY

Membership is FREE

Membership is open to anyone affected by or interested in Kennedy's Disease, including patients, carriers, families, caregivers, and medical professionals.

JOIN THE KDA

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