

GIVE THE MOST PRECIOUS GIFT...

Donating tissues to the FSHD Biospecimen Registry will have a lasting impact on future generations by helping scientists test breakthrough theories, develop new medications and one day find a cure for FSHD. It's simple to donate, there is no cost involved to the donor and the tissue is urgently needed.

Human tissue is precious to researchers developing cures for nearly every disease imaginable.



“Solving FSHD begins with the courage of individuals to donate their tissues to advance science.”

— Daniel Paul Perez
President & CEO FSH Society

THE FSHD BIOSPECIMEN REGISTRY WAS ESTABLISHED BY THE FSH SOCIETY IN PARTNERSHIP WITH NDRI, THE NATION'S LEADING SOURCE FOR HIGH QUALITY BIOSPECIMENS FOR RESEARCH.

The FSH Society is the world's largest non-profit 501(c)(3) patient advocacy group for FSHD. NDRI is a non-profit 501(c)(3) organization that annually ships more than 29,000 biospecimens from our nationwide procurement network to over 500 researchers worldwide.

Make an impact by donating organ or tissue samples.

NDRI makes it easy to contribute to solving complex medical challenges. Organ and tissue donation for research is essential for understanding a disease and can potentially lead to a new treatment or a cure.



National Disease Research Interchange

8 Penn Center, 15th Floor
1628 JFK Boulevard, Philadelphia, PA 19103

(215) 557-7361

(800) 222-NDRI (6374)

info@ndriresource.org

www.ndriresource.org



FSH Society

450 Bedford Street
Lexington MA 02420

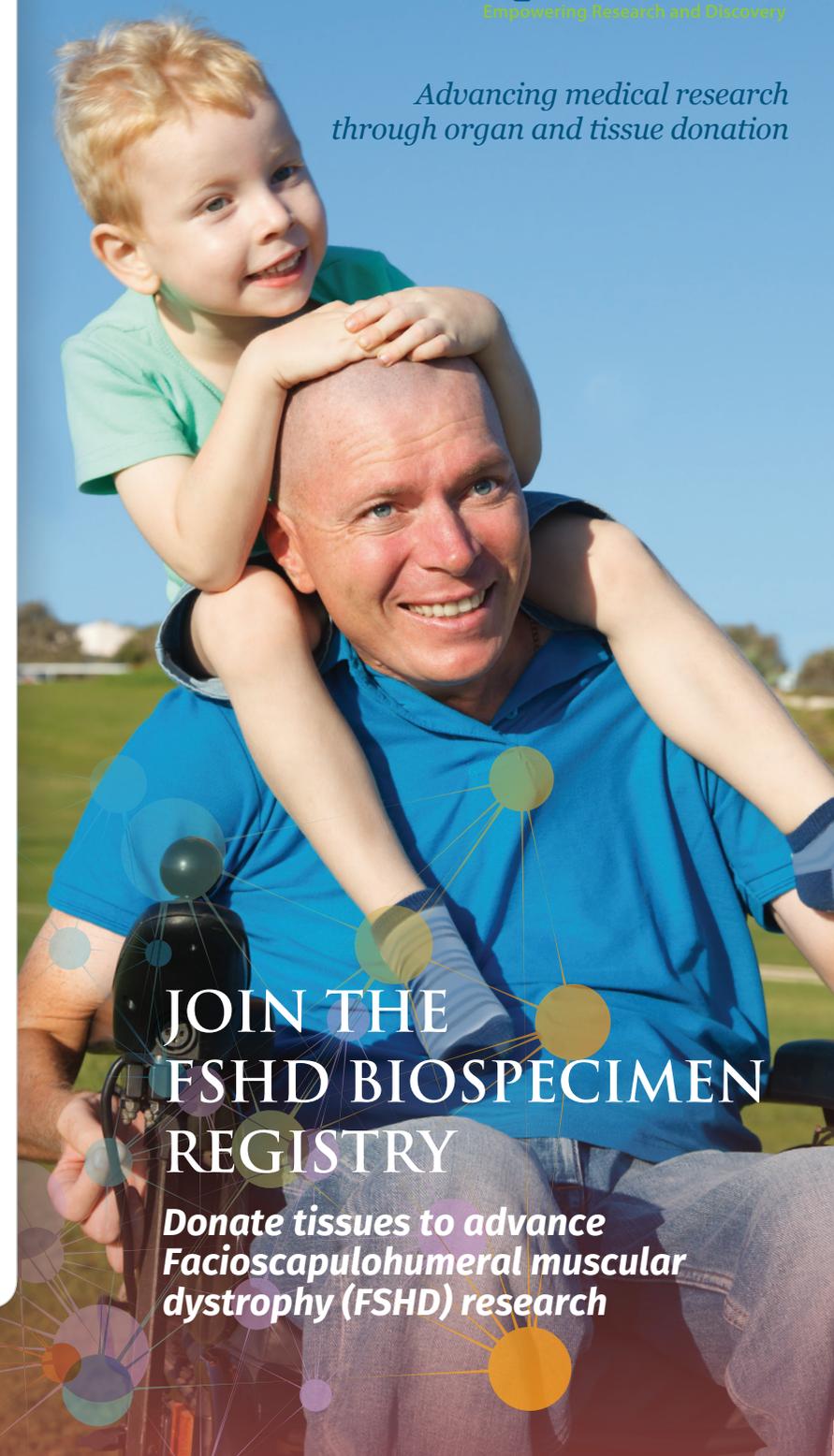
(781) 301-6060

info@fshsociety.org

www.fshsociety.org



Advancing medical research through organ and tissue donation



**JOIN THE
FSHD BIOSPECIMEN
REGISTRY**

**Donate tissues to advance
Facioscapulohumeral muscular
dystrophy (FSHD) research**

WHAT IS FSHD?

Facioscapulohumeral Muscular Dystrophy (FSHD) is among the most common forms of muscular dystrophy, affecting children and adults of both sexes. The cardinal feature of FSHD is the progressive loss of muscle strength. Weakness typically begins in the face (facio), shoulder girdle (scapulo), and upper arms (humeral), as well as the legs and torso, and may progress to affect any skeletal muscle.

- Symptoms can develop at any age, from infancy through advanced age.
- About 4 percent of cases are diagnosed in children under the age of 5.
- Around 25% of patients will require a scooter or wheelchair.
- Less common difficulties include hearing loss and damage to vessels in the retina.

WHY DO WE NEED TISSUE SPECIMENS?

In order to understand and treat FSHD, researchers need to study tissue samples from FSHD patients and unaffected family members (who serve as experimental controls).

WHY DOES THE FSHD BIOSPECIMEN REGISTRY NEED YOU TO SIGN UP?

Arranging for tissue donation from a surgical or postmortem procedure can be exceedingly complicated. Indicating your wishes and taking care of consent forms in advance through this registry greatly facilitates the process.

WHO CAN DONATE?

We encourage donations of tissue from individuals affected by FSHD and from unaffected family members of all ages, from infancy to adulthood. A patient or his/her family may donate tissues for FSHD research by registering with NDRI's Private Donor Program. The FSH Society works in partnership with NDRI to recover the donated tissues from a surgical procedure or after a patient has died.

WHAT IS NDRI'S PRIVATE DONOR PROGRAM?

The Private Donor Program gives individuals and their families an opportunity to leave a meaningful legacy for their loved ones, by providing a simple system through which tissues can be donated for research. NDRI works with you and your family to obtain authorization for donation of tissues from surgery or postmortem, arranges the recovery, and provides the tissues to approved researchers.

To coordinate these recoveries, NDRI partners with Organ Procurement Organizations (OPO), tissue banks, hospitals, pathologists, medical examiners, and tissue recovery specialists. These highly skilled professionals help champion the wishes of NDRI's registered donors.



HOW DOES TISSUE DONATION WORK?

Tissues collected for FSHD will be provided to registered and approved FSHD researchers.

- Some of your health information may be provided to FSHD specific researchers.
- Donated tissues may be placed into a BioBank, and studied for many years.
- Personal identifying information about the donor is removed from the medical data to protect the individual's privacy.
- Only tissues needed for research will be recovered.

Detailed clinical and genetic information will also be collected to observe the presence of disease, thus providing targets for the development of new therapies. There does remain a small potential of genetic data exposure. Participation in the FSHD Biospecimen Registry is voluntary. None of the testing results will be returned to donor relatives or guardians.

WHAT TISSUE SAMPLES ARE NEEDED?

- Facial muscles
- Arm muscles
- Shoulder girdle muscles
- Hip flexors
- Back muscles
- Leg muscles
- Abdominal muscles
- Pectoral muscles
- Diaphragm
- Cochlea (inner ear)
- Retina

Your gift supports critical disease research.
Register today by calling NDRI at (800) 222-6374
or visit the website at ndriresource.org