NATIONAL DISEASE RESEARCH INTERCHANGE

FSHD Tissue Donation Registry

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NDRI’s History and Overview
Mission Statement

NDRI provides human biospecimens to advance biomedical/bioscience research and development worldwide
Who We Are

NDRI was founded in Philadelphia in 1980

What you should know about NDRI

- A 501c3 corporation
- Governed by a board of directors
- NIH funded
- Support for over 30 years by the National Institutes of Health
- 29,000 biospecimens
- Provided to biomedical scientists per year
- Publishing
- 200 hundred publications annually
Funded by the National Institutes of Health
For over 30 years
Additional Funding

Corporate
- Pharma / Biotech Industry

Special Initiatives
- Cystic Fibrosis Foundation Collaboration
- ATSDR/Boston VA ALS Projects
- Joslin Medalist Diabetes Project
- Children’s Tumor Foundation Project
- Facioscapulohumeral Muscular Dystrophy
Types of Tissue Requests

- **NDRI**
  - **Standard Requests**
    - Eyes
    - Solid Organs
    - Tissue Bank Specimens
    - Surgical Specimens
  - **Custom Project Requests**
    - Targeted Sourcing
    - Special Initiatives
    - Enhanced Donor Data
    - Recovery Protocol Development
NDRI Services

- Recruit clients/researchers
- Develop protocols
- Project Management
- Coordinate logistics
- Maintain compliance
- Quality Management System
Biospecimen Application Process

1. Application
   - Tissue needs / donor profile
   - IRB documentation
   - Project synopsis
   - CV / biosketch

2. Feasibility Review
   - Scientific Advisory Council

3. Customized Protocol Development
Standard Authorization / Consent

- Protocol approved by University of Pennsylvania IRB
- Potential access to complete health record
- Authorization for general research including:
  - For profit
  - Therapeutics and diagnostics
  - Genome sequencing
- No payment to donor or family decision maker
Expanded Authorization / Consent

- Project specific IRB approval
- Incorporates additional objectives (e.g. product development)
- Right to withdraw limits
- Addresses risks associated with loss of identity (genotyping)
- Unknown future uses
- Cell line development (unlimited future use)
Key Metrics

- 58,000 Donation Opportunities Nationally
- NDRI 24 / 7 Call Center
- 29,000 Tissues Placed
- 4,600 Diseased Tissues / 82 Diseases
- 500 Researchers Served
Biospecimen Donor Profiles

Deceased Transplant Donors
Organ / Tissue / Eye

Living Patients
Surgical & Explant Tissue

Patients Participating in Clinical Studies

Pre-registered Research Donors

Advancing Medical Research through Organ and Tissue Donation
Nationwide Procurement Network

56 Organ Procurement Organizations
23 Tissue Banks
43 Hospitals
37 Eye Banks
150 Recovery Personnel
NDRI’s Private Donor Program
What to expect from NDRI

- Obtaining consent/authorization
- Create/maintain donor registries
- Develop donation plans to support tissue recovery
- Coordinate all aspects of donation event
- Shipment of donated tissues to researchers
How we work with Patient Advocacy Groups and Clinical Researchers

- PAG or Physician refers donor to NDRI
- Researchers referred by PAG or recruited by NDRI
- PAG or Physician is notified of recovery
- PAG, Physician or Family notifies NDRI of surgery or death

Maintenance

Vetting

Shipment

Coordination
FSHD Tissue Donor Registry

- Surveyed research community
- Authorization and Brochure
- Identify and consent patients
- Donation options
Contact Information

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THANK YOU