
NATIONAL DISEASE RESEARCH INTERCHANGE

FSHD Tissue Donation Registry

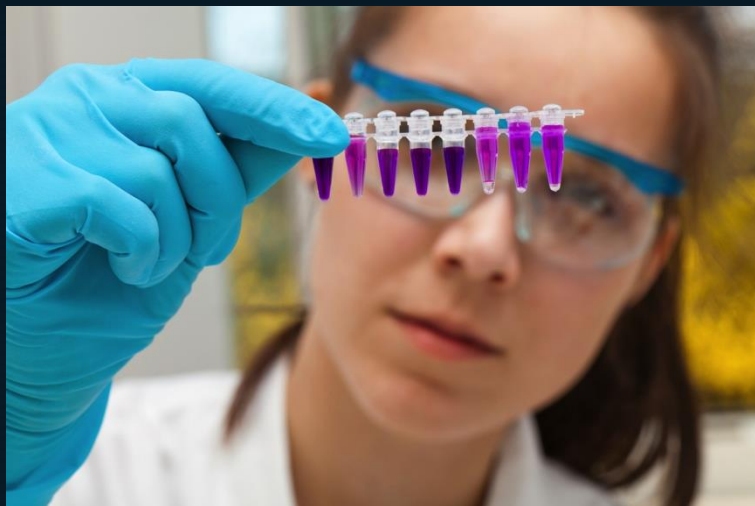
*Denée Tidwell
Partnership Development Manager
NDRI
November 11th, 2016*

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

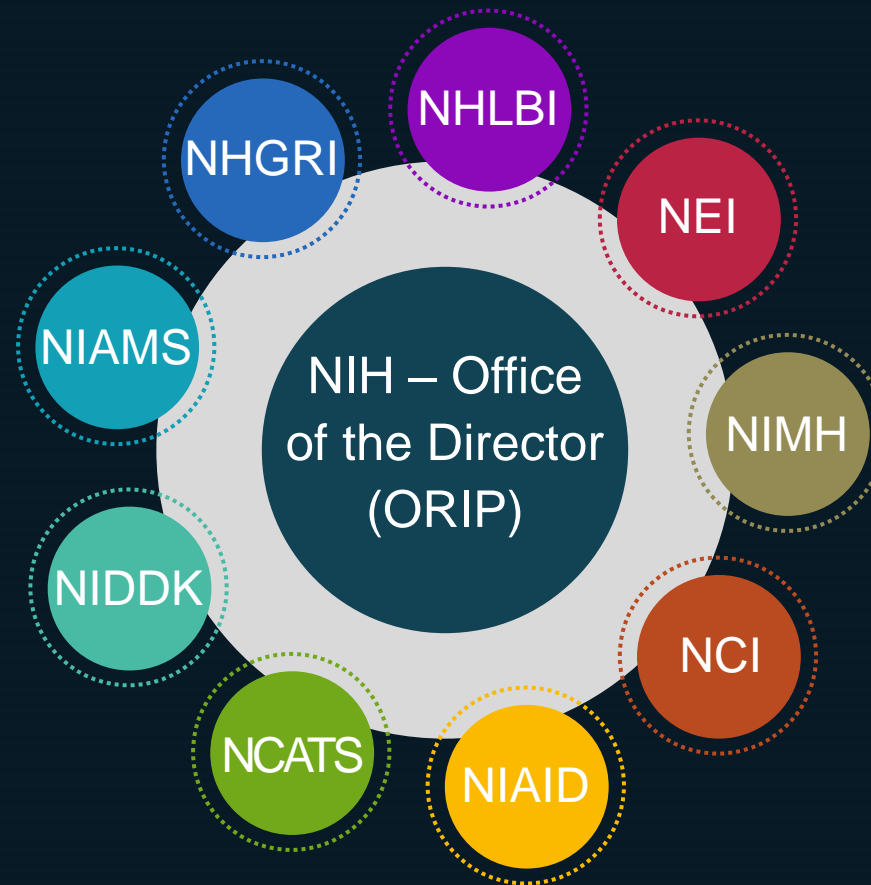


Publishing
200 hundred publications annually

Funded by the National Institutes of Health

For over 30 years

5



| Additional Funding



Corporate

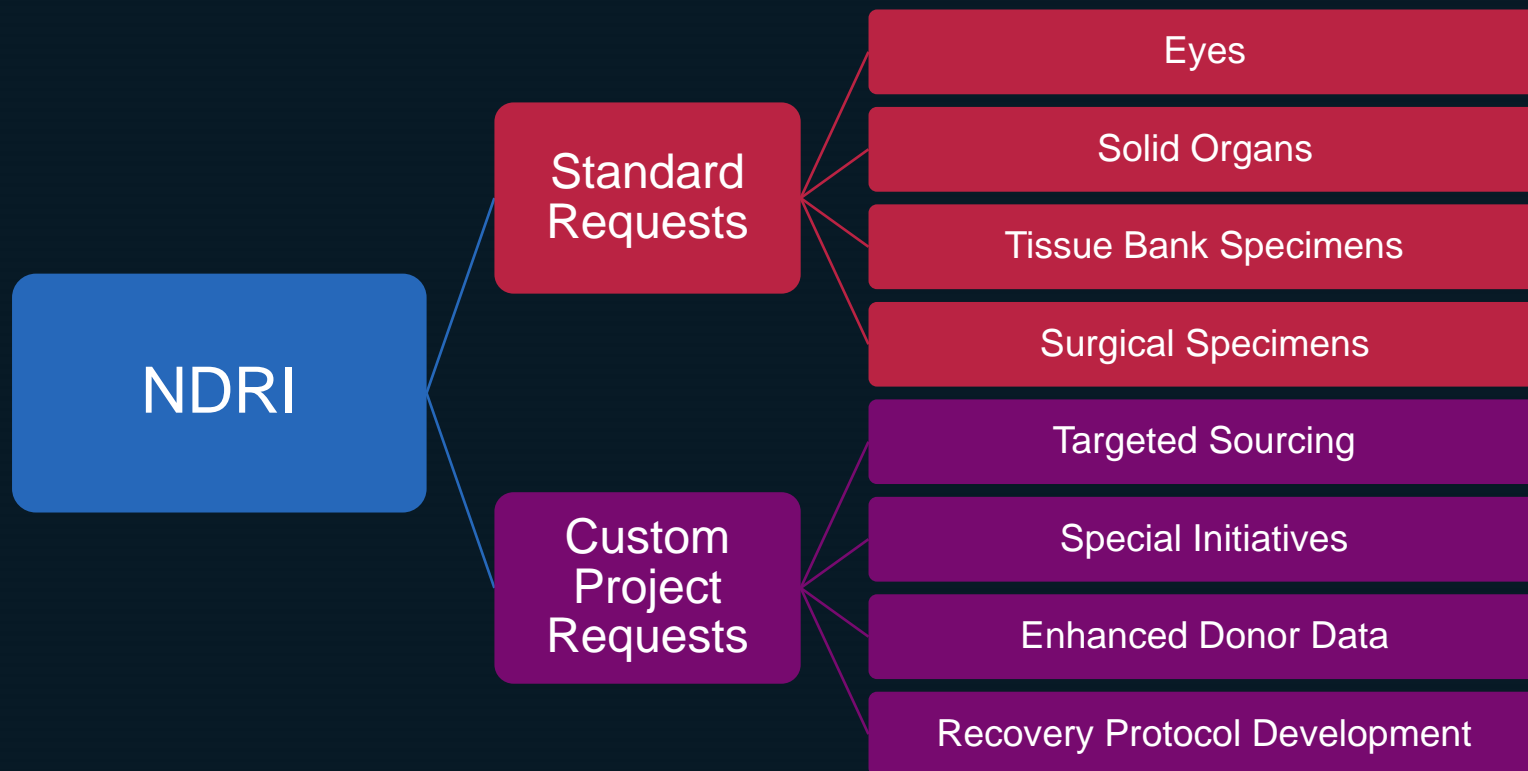
- Pharma / Biotech Industry



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 Services

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

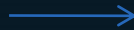
Biospecimen Application Process



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



Addresses risks associated with loss of identity (genotyping)



Incorporates additional objectives (e.g. product development)



Unknown future uses

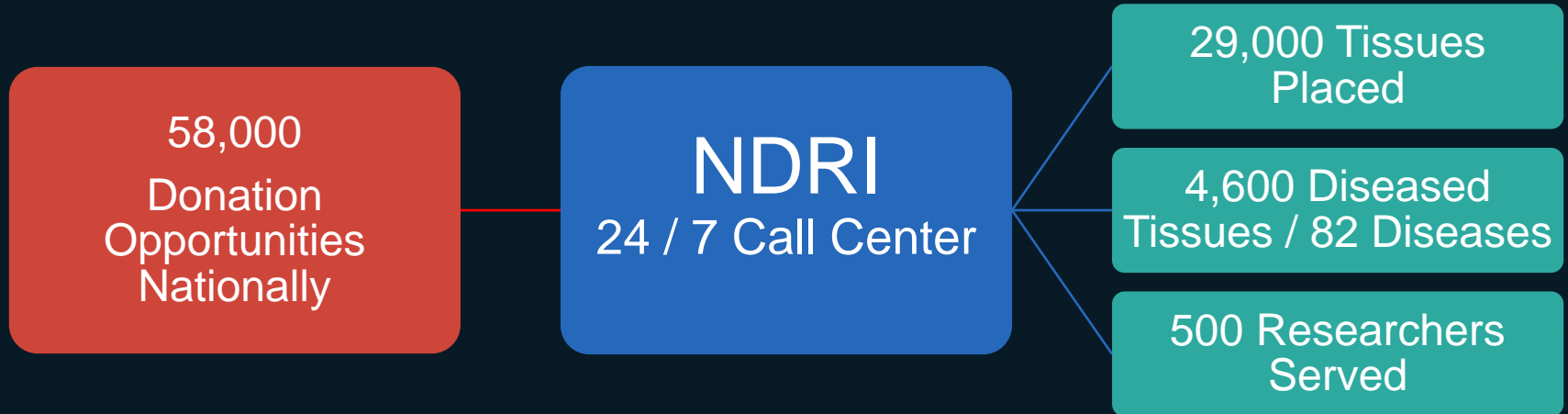


Right to withdraw limits

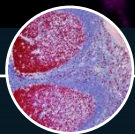
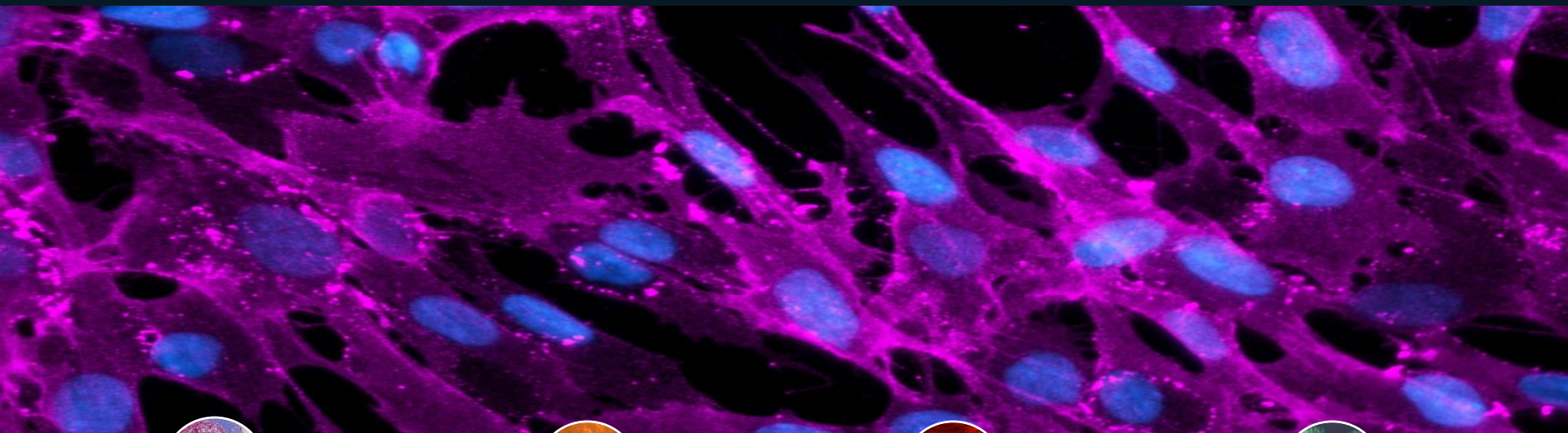


Cell line development (unlimited future use)

| Key Metrics

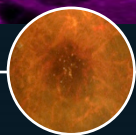


Biospecimen Donor Profiles



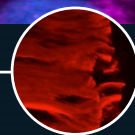
Deceased
Transplant
Donors

Organ / Tissue / Eye



Living
Patients

Surgical & Explant Tissue



Patients
Participating
in Clinical
Studies



Pre-registered
Research
Donors

Nationwide Procurement Network

56

Organ Procurement Organizations

23

Tissue Banks

43

Hospitals

37

Eye Banks

150

Recovery Personnel

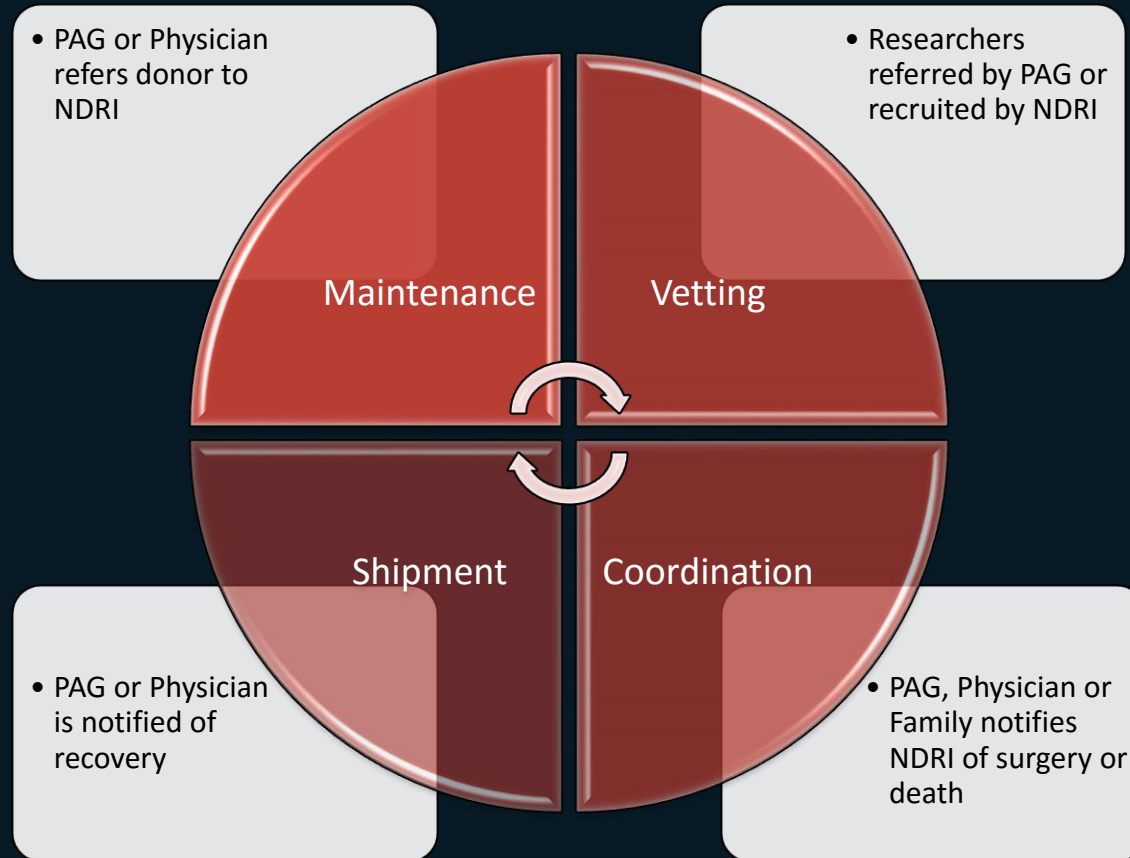


NDRI's Private Donor Program

| 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



| FSHD Tissue Donor Registry

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



Contact Information

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THANK YOU

