


**User Manual:**  
Human Biospecimens/  
Biorepositories Database  
Database Search



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## Overview

The Biospecimens/Biorepositories Web site Rare Disease-HUB (RD-HUB) of the Office of Rare Diseases Research (ORDR) consists of a publicly accessible, searchable, Web-based database (inventory) of biorepositories and their collections of samples. This database facilitates global sharing of material and data among investigators to facilitate research leading to treatments and cures for rare diseases, as well as more common diseases, by improving researchers' access to needed human biospecimens. The goal of RD-HUB is to serve the global research community, the patients and the patient advocacy groups and the large community as well. In addition to assisting the researchers locate specimens, the scope of the RD-HUB includes providing links to best practices for specimen collection, handling, and processing; models and templates for informed consent, and ethical and legal guidelines for handling human subject material for research and treatment; as well as links to related articles and protocols and other useful information.

The database contains seven tabs: (1) Repository, (2) Disease, (3) Specimen Type, (4) Anatomic Source, (5) Processing Method, (6) Storage Method, and (7) Imaging.

When searching the database, you can conduct a general search to obtain a list of all the specimens in our database or a list of particular specimens. To locate specific specimens, select items from the tabs to refine your search. To obtain a comprehensive list, do not select or unselect any checkboxes and click "Search" (located above the "Your Search Selection" textbox). In this user manual, we provide detailed instructions about conducting a search for and locating biospecimens using the seven criteria listed above.

## Search by Repository

a. *Repository* is the tab that allows users to search for biospecimens based on repository name (see Figure 1).

Grayed out letters indicate that no repositories whose names start with that letter have contributed to the RD-HUB Database yet. Grayed out repository names indicate that those repositories have not contributed to the RD-HUB yet.

b. The default setting for the *Repository* tab is “Search All.” The “Search All” feature allows you to obtain a list of all the repositories that have uploaded biospecimen data.

To conduct a search by a specific repository, uncheck the “Search All” checkbox and perform any of the three methods below:

1. Type the name of the repository in the auto-fill textbox, select the repository name from the drop-down list of repositories, and click the “Go” button. Please note that this option does not allow you to select multiple repositories or to search by any other criterion.
2. Use the scrollbar to locate the repository or repositories of interest and select the checkbox(es) next to the repository or repositories for which you wish to obtain biospecimens data. If desired, select additional search criteria from the other tabs. Click the “Search” button (located above the “Your Search Selection” textbox) when you have selected all your search criteria and are ready to execute your search.
3. Click the letter of the alphabet with which the name of your repository of interest begins, locate the repository or repositories of interest, and select the checkbox(es) next to the repository or repositories for which you wish to obtain biospecimens data. If desired, select additional search criteria from the other tabs. Click the “Search” button (located above the “Your Search Selection” textbox) when you have selected all your search criteria and are ready to execute your search.

c. As you make selections, the “Your Search Selections” box dynamically refreshes with the choices made. If you would like to clear your search selections, click the “Clear All” button (located above the “Your Search Selection” textbox).

d. Click “Search.” For more information on search results and refining your search results, please refer to page 18 of this user manual.

Figure 1. Screenshot of RD-HUB *Repository* tab

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# BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)

QUICK DATABASE SEARCH

- Home
- Enter Biorepository Data
- Search the Database
- Contributing Biorepositories
- Other Related Resources
- News and Publications
- Events
- Frequently Asked Questions
- User Manual

## Search the Human Biospecimens/Biorepositories Database

Select items from each tab below to refine your search. For detailed instructions about searching the database, please refer to the [User Manual-Database Search](#).

Please note: *Rare diseases* are labeled with an asterisk (\*) and are linked to disease-specific information Web pages created by the Genetic and Rare Diseases Information Center (GARD). Non-contributing biorepositories and biospecimens not yet available are grayed out or unselectable.

Disease Specimen Type **Repository** Anatomic Source Processing Method Storage Method Imaging

### Your Search Selection

Search All  
Normal- Search All  
Specimen Type- Search All  
Anatomic Source- Search All  
Processing Method- Search All  
Storage Method- Search All  
Imaging- Search All

Search All

- ADA Cell Repository Maturity Onset Diabetes Collection
- AIDS and Cancer Specimen Resource
- Albert Einstein College of Medicine, Department of Pathology and Neuroscience
- Albert Einstein Human Tissue Repository, Albert Einstein College of Medicine
- Athers Neuro pathology Laboratory, Thomas Jefferson University, Department of Neurology
- Alzheimer Resource Center
- Alzheimer's Disease Brain Tissue Bank, Brigham & Women's Hospital, Center for Neurologic Diseases
- Alzheimer's Disease Center: University of Alabama at Birmingham
- Alzheimer's Disease Center: University of Arkansas for Medical Sciences

**Grayed-out letters indicate no repositories whose name starts with that letter have uploaded biospecimens to the database.**

**Grayed-out text indicates no biospecimens have been uploaded by that repository.**

**"Your Search Selection" textbox allows users to see what search criteria they have chosen.**

## Search by Disease

- a. The *Disease* tab is the default tab that displays when first navigating to RD-HUB, which allows users to locate biospecimens from individuals who either have a **disease** (see “All Diseases”) or are **normal** (see “Normal”) (see Figure 2).

**Disease** = specimens showing evidence of disease as reviewed by H & E staining, molecular analysis, genetic analysis, phenotypically affected donor, or other methods

**Normal** = specimens showing no evidence of disease as reviewed by H & E staining, molecular analysis, genetic analysis, phenotypically unaffected donor, or other methods

The “All Diseases” section is divided into two sections under the #...Z pages: (1) Diseases with Specimens and (2) Diseases without Specimens. Only those diseases for which we have specimens will be searchable and will appear under the “Diseases with Specimens.” When a specimen is added for a disease that was included in the “Diseases without Specimens” section, the disease will become searchable and be moved from the “Diseases without Specimens” to the “Diseases with Specimens” section.

*Please note:* “OMIM Number” is grayed out because the database is currently not searchable by this field.

- b. The default setting for the *Disease* tab is “Search All.” The “Search All” feature allows you to obtain a list of all the diseases for which biospecimens data have been uploaded.

To conduct a search by a specific disease, uncheck the “Search All” checkbox and perform any of the three methods below:

1. Type the name of the disease in the auto-fill textbox, select the disease of interest from the drop-down list of diseases, and click the “Go” button. Please note that this option does not allow you to select multiple diseases or to search by any other criterion.
2. Use the scrollbar to locate the disease(s) of interest and select the checkbox(es) next to the disease(s) for which you wish to obtain biospecimens data. If desired, select additional search criteria from the other tabs. Click the “Search” button (located above the “Your Search Selection” textbox) when you have selected all your search criteria and are ready to execute your search.
3. Click the letter of the alphabet with which the name of your disease of interest begins, locate the disease(s) of interest, and select the checkbox(es) next to the disease(s) for which you wish to obtain biospecimens data. If desired, select additional search criteria from the other tabs. Click the “Search” button (located above the “Your Search Selection” textbox) when you have selected all your search criteria and are ready to execute your search.

*Please note:* Grayed out checkboxes are not selectable and indicate that no biospecimens exist in RD-HUB for the selected disease.

- c. An asterisk (\*) next to a disease name indicates that the disease is rare. A rare disease is defined as a disease that affects fewer than 200,000 individuals in the United States.



- d. Diseases with an embedded hyperlink have a Web page on the Office of Rare Diseases Research (ORDR) Web site that provides information and supportive resources. To view the Web page on the ORDR Web site, click the hyperlinked disease of interest.
- e. To locate a biospecimen from a normal specimen, click on “Normal” (see Figure 3).  
*Please note:*
  - “Yes” indicates the specimen shows no evidence of disease as reviewed by H & E staining, molecular analysis, genetic analysis, phenotypically unaffected donor, or other methods
  - “Unknown” indicates it is not known whether the specimen shows evidence of disease as reviewed by H & E staining, molecular analysis, genetic analysis, phenotypically unaffected donor, or other methods
- f. As you make selections, the “Your Search Selections” box dynamically refreshes with the choices made. If you would like to clear your search selections, click the “Clear All” button (located above the “Your Search Selection” textbox).
- g. Click “Search”. For more information on search results and refining your search results, please refer to page 18 of this user manual. If no match is found, you are provided the option to refine your search or conduct a new search (see Figure 11) on page 17.

**Figure 2.** Screenshot of RD-HUB *Disease* tab

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## BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)

QUICK DATABASE SEARCH  **GO**

- + Home
- + Enter Biorepository Data
- + Search the Database
- + Contributing Biorepositories
- + Other Related Resources
- + News and Publications
- + Events
- + Frequently Asked Questions
- + User Manual

### Search the Human Biospecimens/Biorepositories Database

Select items from each tab below to refine your search. For detailed instructions about searching the database, please refer to the [User Manual-Database Search](#).

*Please note: [Rare diseases](#) are labeled with an asterisk (\*) and are linked to disease-specific information Web pages created by the Genetic and Rare Diseases Information Center (GARD). Non-contributing biorepositories and biospecimens not yet available are grayed out or unselectable.*

Repository Disease Specimen Type Anatomic Source Processing Method Storage Method Imaging

[All Diseases](#) | [Normal](#) Or: [OMIM Number](#)

**GO**

# [A](#) [B](#) [C](#) [D](#) [E](#) [F](#) [G](#) [H](#) [I](#) [J](#) [K](#) [L](#) [M](#) [N](#) [O](#) [P](#) [Q](#) [R](#) [S](#) [T](#) [U](#) [V](#) [W](#) [X](#) [Y](#) [Z](#)

**Diseases with specimens**

- Search All
- [10q partial trisomy\\*](#)
- [15q13.3 microdeletion syndrome\\*](#)
- [16p11.2 deletion syndrome\\*](#)
- [17-@BETA HYDROXYSTEROID DEHYDROGENASE III DEFICIENCY](#)
- [17-alpha-hydroxylase deficiency\\*](#)
- [17-beta hydroxysteroid dehydrogenase 3 deficiency\\*](#)
- [17q21.31 microdeletion syndrome\\*](#)
- [18p- syndrome\\*](#)

**Your Search Selection**

- Repository-**  
[Search All](#)
- Disease-**  
[Search All](#)
- Normal-**  
[Search All](#)
- Specimen Type-**  
[Search All](#)
- Anatomic Source-**  
[Search All](#)
- Processing Method-**  
[Search All](#)
- Storage Method-**  
[Search All](#)

**Hyperlink to Web page on ORDR Web site to disease-specific information and supportive resources**

**Asterisk (\*) indicates a rare disease**

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Figure 3. Screenshot of RD-HUB *Normal*

The screenshot displays the RD-HUB website interface. At the top left is the logo for the Office of Rare Diseases Research, National Institutes of Health. The main header reads "BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)". Below the header is a "QUICK DATABASE SEARCH" bar with a "GO" button. A left-hand navigation menu lists various options: Home, Enter Biorepository Data, Search the Database, Contributing Biorepositories, Other Related Resources, News and Publications, Events, Frequently Asked Questions, and User Manual. The main content area is titled "Search the Human Biospecimens/Biorepositories Database" and includes instructions on how to refine the search. A note states that rare diseases are marked with an asterisk and linked to specific information pages. Below this is a search filter interface with tabs for Repository, Disease, Specimen Type, Anatomic Source, Processing Method, Storage Method, and Imaging. The "Disease" tab is selected, and the "Normal" filter is active. A search input field is present with a "GO" button. Below the input field are checkboxes for "Search All", "Yes", and "Unknown". On the right side, a "Your Search Selection" sidebar lists search criteria for each category, all set to "Search All". A "FOLLOW US ON twitter" logo is located in the bottom left corner of the main content area.



## Search by Anatomic Source

- a. The *Anatomic Source* tab allows users to locate biospecimens by the anatomical location from which the biospecimen was taken (see Figure 4).
- b. The default setting for the *Anatomic Source* tab is “Search All.” The “Search All” feature allows users to perform a search and obtain a list of all the anatomic sources for which biospecimen data have been uploaded.

To conduct a search by a specific anatomic location, uncheck the “Search All” checkbox and perform any of the three methods below:

1. Type the name of the specific anatomic source in the auto-fill textbox, select the anatomic source of interest from the drop-down list, and click the “Go” button. Please note that this option does not allow you to select multiple anatomic sources or to search by any other criterion.
2. Use the scrollbar to locate the anatomic source(s) of interest and select the checkbox(es) next to the anatomic source(s) for which you wish to obtain biospecimens data. If desired, select additional search criteria from the other tabs. Click the “Search” button (located above the “Your Search Selection” textbox) when you have selected all your search criteria and are ready to execute your search.
3. Click the letter of the alphabet with which the name of your anatomic source of interest begins, locate the anatomic source of interest, and select the checkbox(es) next to the anatomic source for which you wish to obtain biospecimens data. If desired, select additional search criteria from the other tabs. Click the “Search” button (located above the “Your Search Selection” textbox) when you have selected all your search criteria and are ready to execute your search.

*Please note:* Grayed out letters indicate that no biospecimens exist in RD-HUB for the anatomic sources whose names start with that letter. Grayed out anatomic sources indicate that no biospecimens have been uploaded to RD-HUB for that disease.

- c. As you make selections, the “Your Search Selections” box dynamically refreshes with the choices made. If you would like to clear your search selections, click the “Clear All” button (located above the “Your Search Selection” textbox).
- d. Click “Search”. For more information on search results and refining your search results, please refer to page 18 of this user manual. If no match is found, you are provided the option to refine your search or conduct a new search (see Figure 11) on page 17.

Figure 4. Screenshot of RD-HUB *Anatomic Source* tab

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# BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)

QUICK DATABASE SEARCH

- Home
- Enter Biorepository Data
- Search the Database
- Contributing Biorepositories
- Other Related Resources
- News and Publications
- Events
- Frequently Asked Questions
- User Manual

## Search the Human Biospecimens/Biorepositories Database

Select items from each tab below to refine your search. For detailed instructions about searching the database, please refer to the [User Manual-Database Search](#).

Please note: *Rare diseases* are labeled with an asterisk (\*) and are linked to disease-specific information Web pages created by the Genetic and Rare Diseases Information Center (GARD). Non-contributing biorepositories and biospecimens not yet available are grayed out or unselectable.

Repository Disease Specimen Type **Anatomic Source** Processing Method Storage Method Imaging

**SEARCH** **CLEAR ALL**

### Your Search Selection

- Repository-**  
Search All
- Disease-**  
Search All
- Normal-**  
Search All
- Specimen Type-**  
Search All
- Anatomic Source-**  
Search All
- Processing Method-**  
Search All
- Storage Method-**  
Search All
- Imaging-**  
Search All

ABCDEFGHIJKLMNOPQRSTUVWXYZ

- Search All
- Adipose Tissue
- Adrenal Gland
- Amniotic Fluid
- Anus
- Aorta
- Appendix
- Arm
- Artery
- Basal Ganglia
- Bile Duct

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## Search by Specimen Type, Processing Method, Storage Method, and Imaging

- a. The default setting for the *Specimen Type*, *Processing Method*, *Storage Method*, and *Imaging* tabs is “Search All.”

To conduct a search by a specific option, uncheck the “Search All” checkbox and select the checkbox next to the specific selection(s) of interest (see Figures 5, 6, 7, 8).

*Please note:* Grayed out letters indicate that no biospecimens exist in the RD-HUB for the specimen type, processing method, storage method, or imaging option(s) whose names start with that letter. Grayed out options under a given letter indicate that no biospecimens have been uploaded to the RD-HUB for that option.

- b. As you make selections, the “Your Search Selections” box dynamically refreshes with the choices made. If you would like to clear your search selections, click the “Clear All” button (located above the “Your Search Selection” textbox).
- c. Click “Search”. For more information on search results and refining your search results, please refer to page 18 of this user manual. If no match is found, you are provided the option to refine your search or conduct a new search (see Figure 11) on page 17.

Figure 5. Screenshot of RD-HUB *Specimen Type* tab

The screenshot displays the RD-HUB interface. At the top left is the logo for the Office of Rare Diseases Research, National Institutes of Health. The main header reads "BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)". Below the header is a "QUICK DATABASE SEARCH" box with a "GO" button. A left sidebar contains navigation links: Home, Enter Biorepository Data, Search the Database, Contributing Biorepositories, Other Related Resources, News and Publications, Events, Frequently Asked Questions, and User Manual. A "FOLLOW US ON twitter" button is also present. The main content area is titled "Search the Human Biospecimens/Biorepositories Database" and includes instructions to select items from tabs: Repository, Disease, Specimen Type (highlighted with a blue arrow), Anatomic Source, Processing Method, Storage Method, and Imaging. A "SEARCH" button and "CLEAR ALL" button are located to the right of the tabs. Below the tabs is a list of specimen types with checkboxes, all of which are checked: Search All, Bile, Body fluid, Bronchoalveolar Lavage Fluid, Buffy Coat, Cell, Cytoplasmic RNA, DNA, Feces, Hair, Lavage, White Blood Cells, Metastatic Malignant Neoplasm, and Milk, Human. On the right side, a "Your Search Selection" panel lists the selected categories: Repository- Search All, Disease- Search All, Normal- Search All, Specimen Type- Search All, Anatomic Source- Search All, Processing Method- Search All, Storage Method- Search All, and Imaging- Search All.

Figure 6. Screenshot of RD-HUB *Processing Method* tab

The screenshot displays the 'Processing Method' tab of the RD-HUB database search interface. The page header includes the 'Office of Rare Diseases Research' logo and the title 'BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)'. A search bar with a 'GO' button is located at the top right. On the left, a navigation menu lists various options like 'Home', 'Enter Biorepository Data', and 'User Manual'. The main content area is titled 'Search the Human Biospecimens/Biorepositories Database' and contains instructions for refining the search. A horizontal tab bar at the top of the main content area includes 'Repository', 'Disease', 'Specimen Type', 'Anatomic Source', 'Processing Method' (highlighted in green with a blue arrow), 'Storage Method', and 'Imaging'. Below this tab bar is a list of search filters with checkboxes. The 'Processing Method' section includes options like 'Cell culture', 'Cell line', 'Citrate', 'Dried specimen', 'Edetic acid', 'Ethanol', 'Fixed Specimen', 'Formaldehyde', 'Formalin-fixed paraffin-embedded', 'Fresh Specimen', 'Frozen Specimen', 'Heparin', and 'Microdissection'. On the right side, a 'Your Search Selection' panel shows the current search criteria for each category, all set to 'Search All'. A 'FOLLOW US ON twitter' button is visible in the bottom left corner.

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# BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)

QUICK DATABASE SEARCH

- Home
- Enter Biorepository Data
- Search the Database
- Contributing Biorepositories
- Other Related Resources
- News and Publications
- Events
- Frequently Asked Questions
- User Manual

## Search the Human Biospecimens/Biorepositories Database

Select items from each tab below to refine your search. For detailed instructions about searching the database, please refer to the [User Manual-Database Search](#).

Please note: *Rare diseases* are labeled with an asterisk (\*) and are linked to disease-specific information Web pages created by the Genetic and Rare Diseases Information Center (GARD). Non-contributing biorepositories and biospecimens not yet available are grayed out or unselectable.

Repository Disease Specimen Type Anatomic Source **Processing Method** Storage Method Imaging

### Your Search Selection

**Repository-**  
Search All

**Disease-**  
Search All

**Normal-**  
Search All

**Specimen Type-**  
Search All

**Anatomic Source-**  
Search All

**Processing Method-**  
Search All

**Storage Method-**  
Search All

**Imaging-**  
Search All

Search All

- Cell culture
- Cell line
- Citrate
- Dried specimen
- Edetic acid
- Ethanol
- Fixed Specimen
- Formaldehyde
- Formalin-fixed paraffin-embedded
- Fresh Specimen
- Frozen Specimen
- Heparin
- Microdissection

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Figure 7. Screenshot of RD-HUB *Storage Method* tab

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# BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)

QUICK DATABASE SEARCH  **GO**

- Home
- Enter Biorepository Data
- Search the Database
- Contributing Biorepositories
- Other Related Resources
- News and Publications
- Events
- Frequently Asked Questions
- User Manual

## Search the Human Biospecimens/Biorepositories Database

Select items from each tab below to refine your search. For detailed instructions about searching the database, please refer to the [User Manual-Database Search](#).

*Please note: [Rare diseases](#) are labeled with an asterisk (\*) and are linked to disease-specific information Web pages created by the Genetic and Rare Diseases Information Center (GARD). Non-contributing biorepositories and biospecimens not yet available are grayed out or unselectable.*

Repository Disease Specimen Type Anatomic Source Processing Method **Storage Method** Imaging

### Your Search Selection

- Repository-**  
Search All
- Disease-**  
Search All
- Normal-**  
Search All
- Specimen Type-**  
Search All
- Anatomic Source-**  
Search All
- Processing Method-**  
Search All
- Storage Method-**  
Search All
- Imaging-**  
Search All

Search All

- 20 Degrees Celsius Freezer
- 80 Degrees Celsius Freezer
- Frozen in Liquid Nitrogen
- Liquid Nitrogen Vapor
- None
- Other
- Refrigerated (4 Degrees Celsius)
- Room Temperature
- Unknown

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Figure 8. Screenshot of RD-HUB *Imaging* tab

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# BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)

QUICK DATABASE SEARCH  **GO**

- Home
- Enter Biorepository Data
- Search the Database
- Contributing Biorepositories
- Other Related Resources
- News and Publications
- Events
- Frequently Asked Questions
- User Manual

## Search the Human Biospecimens/Biorepositories Database

Select items from each tab below to refine your search. For detailed instructions about searching the database, please refer to the [User Manual-Database Search](#).

*Please note: [Rare diseases](#) are labeled with an asterisk (\*) and are linked to disease-specific information Web pages created by the Genetic and Rare Diseases Information Center (GARD). Non-contributing biorepositories and biospecimens not yet available are grayed out or unselectable.*

Repository Disease Specimen Type Anatomic Source Processing Method Storage Method **Imaging** **SEARCH** **CLEAR ALL**

**Your Search Selection**

- Repository-**  
Search All
- Disease-**  
Search All
- Normal-**  
Search All
- Specimen Type-**  
Search All
- Anatomic Source-**  
Search All
- Processing Method-**  
Search All
- Storage Method-**  
Search All
- Imaging-**  
Search All

- Search All
- Histopathology/digital microscopy
- MRI
- Not applicable
- Other
- PET/CT
- Photo
- X-Ray

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## Quick Database Search

- a. The *Quick Database Search* textbox (located on the upper right-hand side of the Web site) allows users to perform a keyword search of RD-HUB (see Figure 9).
- b. Users can enter a keyword, disease, or repository name.
- c. Once a keyword has been entered, either a list of your search results (see Figure 10) or a message stating that no match was found will display. If no match is found, the user is provided the option to refine the search or conduct a new search (see Figure 11).
- d. Click “Go.” For more information on search results and refining your search results, please refer to page 18 of this user manual. If no match is found, the user is provided the option to refine the search or conduct a new search (see below Figure 11).

**Figure 9.** Screenshot of sample search of *Quick Database Search* Textbox

The screenshot displays the website interface for the Office of Rare Diseases Research, National Institutes of Health. The main header reads "BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)". A search bar labeled "QUICK DATABASE SEARCH" contains the text "cancer", with a blue arrow pointing to it. A yellow "GO" button is to the right of the search bar. On the left, a navigation menu includes links for Home, Enter Biorepository Data, Search the Database, Contributing Biorepositories, Other Related Resources, News and Publications, Events, Frequently Asked Questions, and User Manual. The main content area features an "Overview" section with a welcome message and a "Goals" section with five numbered points. At the bottom, there are buttons for "Enter Biorepository Data" and "Search the Database", along with a note about required fields for data entry. The footer contains the NIH logo, navigation links (Home, Contact Us, Disclaimer, Privacy Policy), and the text "NATIONAL INSTITUTES OF HEALTH".

Figure 10. Screenshot of sample search using the *Quick Database Search*

The screenshot shows the website header with the logo for the Office of Rare Diseases Research, National Institutes of Health. The main title is "BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)". Below the header is a search bar labeled "QUICK DATABASE SEARCH" with the text "cancer" entered and a "GO" button. A navigation menu on the left includes links for Home, Enter Biorepository Data, Search the Database, Contributing Biorepositories, Other Related Resources, News and Publications, Events, Frequently Asked Questions, and User Manual. The main content area is titled "Search the Human Biospecimens/Biorepositories Database" and contains a table with search results.

Disease	Specimen Type	Anatomic Source	Processing Method	Sample Count	Repository	More Details
Familial prostate cancer	Other	Bile Duct	Cell line	Unknown	<a href="#">NCI Cooperative Human Tissue Network (CHTN)</a>	<a href="#">View</a>
Familial prostate cancer		Bile Duct	Cell line		<a href="#">National Institute on Drug Abuse (NIDA) Center for Genetic Studies</a>	<a href="#">View</a>
Familial prostate cancer		Bile Duct	Cell line		<a href="#">National Institute on Drug Abuse (NIDA) Center for Genetic Studies</a>	<a href="#">View</a>

Figure 11. Screenshot of sample search using the *Quick Database Search* for a disease for which no biospecimens are available

The screenshot shows the same website header and navigation menu as Figure 10. The search bar is empty. The main content area is titled "Search the Human Biospecimens/Biorepositories Database" and contains a message: "Our database has no specimens that match your search criteria. Please try again being less specific. If your search does not yield results, please visit us again at a later date, as biospecimens meeting your search criteria may become available." Below the message are two buttons: "Refine Existing Search" and "New Search", with blue arrows pointing to them. At the bottom of the page, there is a footer with the text "FOLLOW US ON twitter" and a Twitter logo, and a footer with the text "Home | Contact Us | Disclaimer | Privacy Policy" and the National Institutes of Health logo.



## Search Results

- a. The initial results screen shows a summary of your search results (see Figure 12).
- b. The table with the search results contains the following sortable columns:
  - o Disease
  - o Specimen Type
  - o Anatomic Source
  - o Processing Method
  - o Samples
  - o Repository
- c. Click the “View” link in the row for the biospecimen for which you are interested in seeing more details. Once you click “View,” a pop-up window will appear with additional information about the biospecimen and the biospecimen donor (see Figure 13).

**Figure 12.** Screenshot of sample search results

The screenshot shows the 'Biospecimens/Biorepositories: Rare Disease-HUB (RD-HUB)' website. The header includes the Office of Rare Diseases Research logo and the title 'BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)'. Below the header is a 'QUICK DATABASE SEARCH' bar with a 'GO' button. The main content area is titled 'Search the Human Biospecimens/Biorepositories Database' and contains a table with the following columns: Disease, Specimen Type, Anatomic Source, Processing Method, Sample Count, Repository, and More Details. The table lists 10 results for '10q partial trisomy', all with 'Bile' as the specimen type and 'Adipose Tissue' as the anatomic source. Each row has a 'View' link in the 'More Details' column. A callout box points to one of the 'View' links with the text: 'Click “View” to obtain detailed information about the biospecimen and the contact information for the repository'. The left sidebar contains navigation links such as 'Home', 'Enter Biorepository Data', 'Search the Database', and 'User Manual'. A 'FOLLOW US ON twitter' button is also visible.

Disease	Specimen Type	Anatomic Source	Processing Method	Sample Count	Repository	More Details
10q partial trisomy	Bile	Adipose Tissue	Cell culture		National Institute on Drug Abuse (NIDA) Center for Genetic Studies	<a href="#">View</a>
10q partial trisomy	Bile	Adipose Tissue	Cell culture		National Institute on Drug Abuse (NIDA) Center for Genetic Studies	<a href="#">View</a>
10q partial trisomy	Bile	Adipose Tissue	Cell culture		National Institute on Drug Abuse (NIDA) Center for Genetic Studies	<a href="#">View</a>
10q partial trisomy	Bile	Adipose Tissue	Cell culture		National Institute on Drug Abuse (NIDA) Center for Genetic Studies	<a href="#">View</a>
10q partial trisomy	Bile	Adipose Tissue	Cell culture		National Institute on Drug Abuse (NIDA) Center for Genetic Studies	<a href="#">View</a>
10q partial trisomy	Bile	Adipose Tissue	Cell culture		National Institute on Drug Abuse (NIDA) Center for Genetic Studies	<a href="#">View</a>
10q partial trisomy	Bile	Adipose Tissue	Cell culture		National Institute on Drug Abuse (NIDA) Center for Genetic Studies	<a href="#">View</a>
10q partial trisomy	Bile	Adipose Tissue	Cell culture		National Institute on Drug Abuse (NIDA) Center for Genetic Studies	<a href="#">View</a>
10q partial trisomy	Bile	Adipose Tissue	Cell culture		National Institute on Drug Abuse (NIDA) Center for Genetic Studies	<a href="#">View</a>
10q partial trisomy	Bile	Adipose Tissue	Cell culture		National Institute on Drug Abuse (NIDA) Center for Genetic Studies	<a href="#">View</a>

## Search Results Details

- Clicking “View” for any result will display a pop-up window with detailed information (see Figure 12).
- Click the “Show Full Info” link next to the *Description* field to learn about the purpose of the biorepository and the types of biospecimens it provides. Click the “Hide Info” link next to the *Description* field to hide the text in the field.
- Click “Print Details” to print the full contents of the pop-up window.
- Click the “X” in the upper right corner to close out of the pop-up window and return to the *Search Results* Web page.

Figure 13. Screenshot of detailed search results

**Search Result Details**

**Primary Contact**  
Name:  
Telephone:  
E-mail:

**Biorepository**  
**Name:** National Institute on Drug Abuse (NIDA) Center for Genetic Studies  
**Description:** [Show Full Info](#)  
**URL:** <http://zork.wustl.edu/nida/>

**Biospecimen**  
**Specimen ID:**  
**Specimen URL:**  
**Disease:** [10q partial trisomy](#)  
**OMIM:**  
**Normal:**  
**Anatomic Source:** Adipose Tissue  
**Tissue Donor:**  
**Storage Method:** -20 Degrees Celsius Freezer  
**Processing Method :** Cell culture  
**Specimen Type:** Bile  
**Type of Consent:** Other  
**Imaging:** PET/CT  
**Is there an associated cost?**  
**Is there a cost for shipping and handling?**  
**Sample Count:**  
**Ethnicity:**  
**Race:**  
**Gender:**  
**Patient Age:**

**Optional Information:**

Histopathologic information available?	Family history available?
Lab data available?	Participant follow-up available?
Matched specimens available?	Treatment information available?
Additional patient demographic available?	Medical history available?
Are genetic testing results available?	