



**User Manual:**  
Human Biospecimens/  
Biorepositories Database  
Data Entry



## Table of Contents

Overview .....	3
Registering your repository .....	4
Obtaining log-in credentials .....	6
Repository not registered	
Repository registered	
Users .....	6
Adding	
Disabling	
Biospecimens .....	7
Uploading Biospecimens	
Via Excel	
Manually	
Editing Biospecimens	
Via Excel	
Manually	
Deleting Biospecimens	
All Samples	
Select Samples	
Forgotten Log-in Credentials .....	20
Technical Difficulties .....	20

## 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.

# Registering your Repository

To enter your repository data, you must register your repository.

To register your repository with RD-HUB, follow the steps below.

1. Complete the online form available at the following hyperlink:  
<https://biospecimens.ordr.info.nih.gov/Biorepositories-CMS/Account/Register.aspx> (see Figure 1).  
*Please note:* All the fields on the online form are required to successfully submit your request.
2. Expect to receive an e-mail containing your log-in credentials within two business days of submitting your request. If you do not receive an e-mail from us within two business days of submitting your request, please contact Yaffa Rubinstein, Ph.D., at [Yaffa.Rubinstein@nih.gov](mailto:Yaffa.Rubinstein@nih.gov).

**Figure 1.** Online registration form for new repositories

The screenshot shows the 'Register Your Biorepository' form on the NIH website. The header includes the NIH logo and the text 'BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)'. A navigation menu on the left lists various options like 'Home', 'Enter Biorepository Data', and 'Search the Database'. The main form area contains the following fields and instructions:

- Primary Contact:**
  - First Name:
  - Last Name:
  - Telephone:  (e.g., XXX-XXX-XXXX)
- Biorepository Information:**
  - E-mail:
  - Biorepository:
- Repository Description:**   
(Please provide the purpose of the biorepository, and the types of biospecimens in your collection.)
- Repository URL:**

At the bottom of the form are 'Cancel' and 'Submit' buttons. The footer contains the NIH logo and navigation links: Home | Contact Us | Disclaimer | Privacy Policy.

## Obtaining Log-in Credentials

### *Repository Not Registered*

If your repository is not registered with RD-HUB, you will need to register your repository prior to obtaining log-in credentials. Please refer to the “Registering a Repository” section on page 4 of this user manual.

### *Repository Registered*

If your repository is registered with RD-HUB, you can obtain log-in credentials by contacting Yaffa Rubinstein, Ph.D., at [Yaffa.Rubinstein@nih.gov](mailto:Yaffa.Rubinstein@nih.gov).

*Please note:* Once you have been added as a user for a given repository, you will receive an e-mail containing your log-in credentials.

## Users

Each repository will be issued a primary user name and a password. This is usually given to the individual who is in charge of the repository (PIs, coordinators, managers, etc). However, each repository can request additional usernames and passwords.

### *Adding Users:*

If your repository is registered with RD-HUB, you can add users by contacting Yaffa Rubinstein, Ph.D., at [Yaffa.Rubinstein@nih.gov](mailto:Yaffa.Rubinstein@nih.gov).

### *Disabling Users:*

We recommend disabling users when they are no longer associated with the repository, or when the user’s access to the repository has expired. To disable a user, please send an e-mail to Yaffa Rubinstein, Ph.D., at [Yaffa.Rubinstein@nih.gov](mailto:Yaffa.Rubinstein@nih.gov).

## Biospecimens

Biospecimens can be uploaded via Excel or manually. Excel is the preferred choice and provides a repeatable method over time. Excel provides the user two options: (1) to append to existing biospecimen records, or (2) to overwrite existing biospecimen records in the database for your repository.

*Please note:* The “Overwrite” option replaces all previously uploaded data by the newly uploaded data.

Below we provide instructions on uploading and entering biospecimens data via Excel and manually.

### *Uploading Biospecimens data via Excel*

1. Log into your repository’s account by clicking “Enter Biorepository Data” on the left menu and entering your Username and Password (see Figures 2 and 3).

**Figure 2.** Screenshot of the left menu

Office of Rare Diseases Research  
National Institutes of Health

# 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

## Overview

Welcome to the Biospecimens/Biorepositories Website: Rare Disease-HUB (RD-HUB) of the Office of Rare Diseases Research (ORDR). This Website contains a searchable database of biospecimens collected, stored, and distributed by biorepositories in the United States and around the globe.

## Goals

1. To help and assist interested parties and investigators search, locate, and identify desired biospecimens needed for their research.
2. To facilitate collaboration and sharing of material and data among investigators across the globe.
3. To accelerate research to facilitate the discovery of new treatments, therapeutics and eventually cures for rare diseases as well as common diseases.
4. To identify, locate and increase the awareness of existing biorepositories across the globe.
5. To link the RD-HUB to the Global Rare Diseases Registry (GRDR). To learn more about the GRDR, please visit [http://rarediseases.info.nih.gov/Patient\\_Registries](http://rarediseases.info.nih.gov/Patient_Registries).

FOLLOW US ON

Home | Contact Us | Disclaimer | Privacy Policy

**Figure 3.** Screenshot of log-in screen for accessing your biorepository's account

Office of Rare Diseases Research  
National Institutes of Health

# 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

## Enter Biorepository Data

Sign in to your biorepository's account.

Username:  (e.g., bsmith, bsmith@email.com)

Password:

[I cannot access my account](#)

FOLLOW US ON

Home | Contact Us | Disclaimer | Privacy Policy

NATIONAL INSTITUTES OF HEALTH

2. Visit the Biospecimens tab (see Figure 4).  
*Please note:* The date and time stamp associated with you records so you can determine the last time you modified your records.
3. Click “Upload by Excel” (see Figure 4).

Figure 4. Biospecimens tab

Biospecimens can be uploaded via Excel or manually. Please review the [user manual](#) for entering data. To upload biospecimens via Excel, click on the "Upload by Excel" link below. To manually input data about a biospecimen, click on the "Add New Biospecimen" link below.

The last time your biorepository uploaded data was on 7/8/2011 at 11:54 AM.

[Upload by Excel](#)

OMIM#	Disease	Anatomic Source	Tissue Donor	Consent	Processing Method	Storage Method	# of Samples	
	MACULAR DYSTROPHY, RETINAL, 1, NORTH CAROLINA TYPE; MCDR1;;FOVEAL DYSTROPHY, PROGRESSIVE;; RETINAL PIGMENT EPITHELIAL DYSTROPHY, CENTRAL;; NORTH CAROLINA MACULAR DYSTROPHY; NCMD;; CENTRAL AREOLAR PIGMENT EPITHELIAL DYSTROPHY; CAPED	Cranial Nerve			Touch Prep Slides	-80 Degrees Celsius Freezer		<a href="#">Edit</a> <a href="#">Delete</a>
	Normal	Anus			Citrate	Refrigerated (4 Degrees Celsius)	201-500	<a href="#">Edit</a> <a href="#">Delete</a>
	Insulinoma	Bladder			Citrate	None		<a href="#">Edit</a> <a href="#">Delete</a>

4. Read the instructions carefully (see Figure 5).
5. Click "Excel template" to save the downloadable Excel template (see Figure 5). Please be sure to save the Excel file as an .xls file. Some of the data fields of the Excel template have drop-down menus that can be used for selecting permissible values. You can also copy and paste your data into the Excel template. If you choose to import your data into the spreadsheet from other sources, the drop-down menu functionality may be overwritten. However, if your data is in tab delimited format and is pasted into the spreadsheet, the drop-down functionality will be preserved.

*Please note:* Changes will be made to the Excel template; therefore, we recommend you note the last modified date located next to the link for downloading the Excel template.

6. Carefully review the instructions and permissible values tab located in tabs 2 and 3 of the downloadable Excel template (see Figure 6).

Figure 5. Uploading via Excel

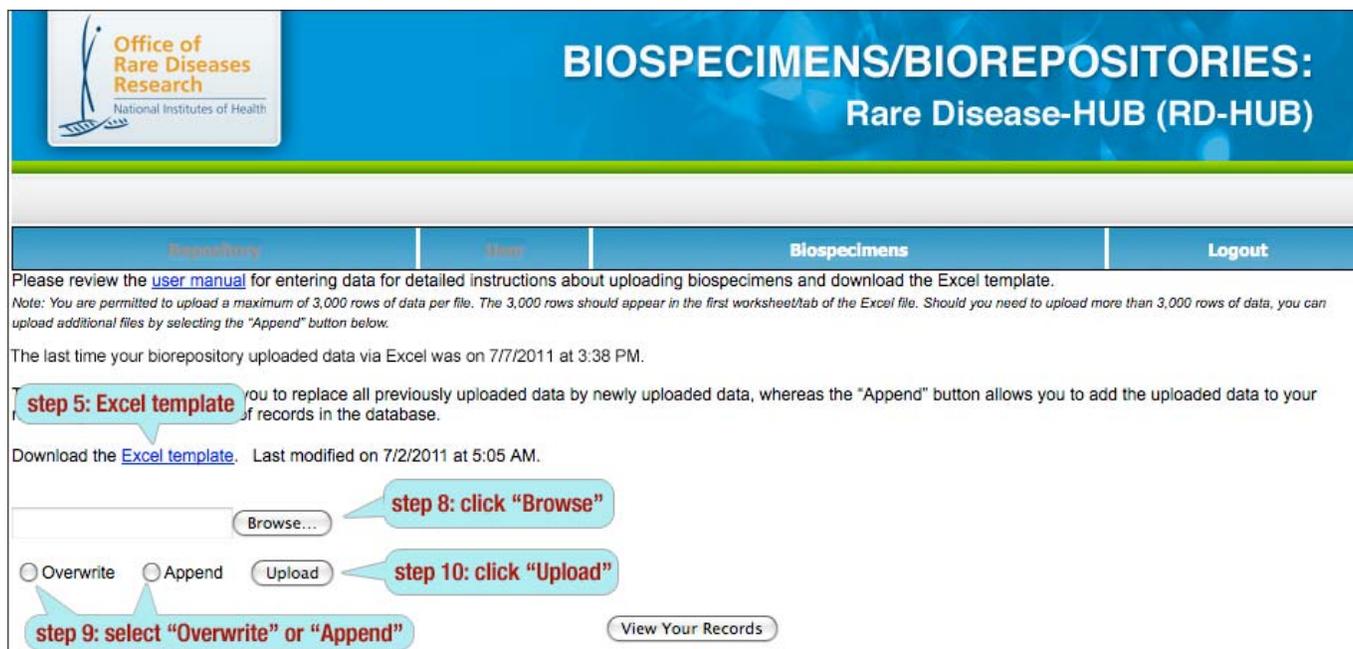
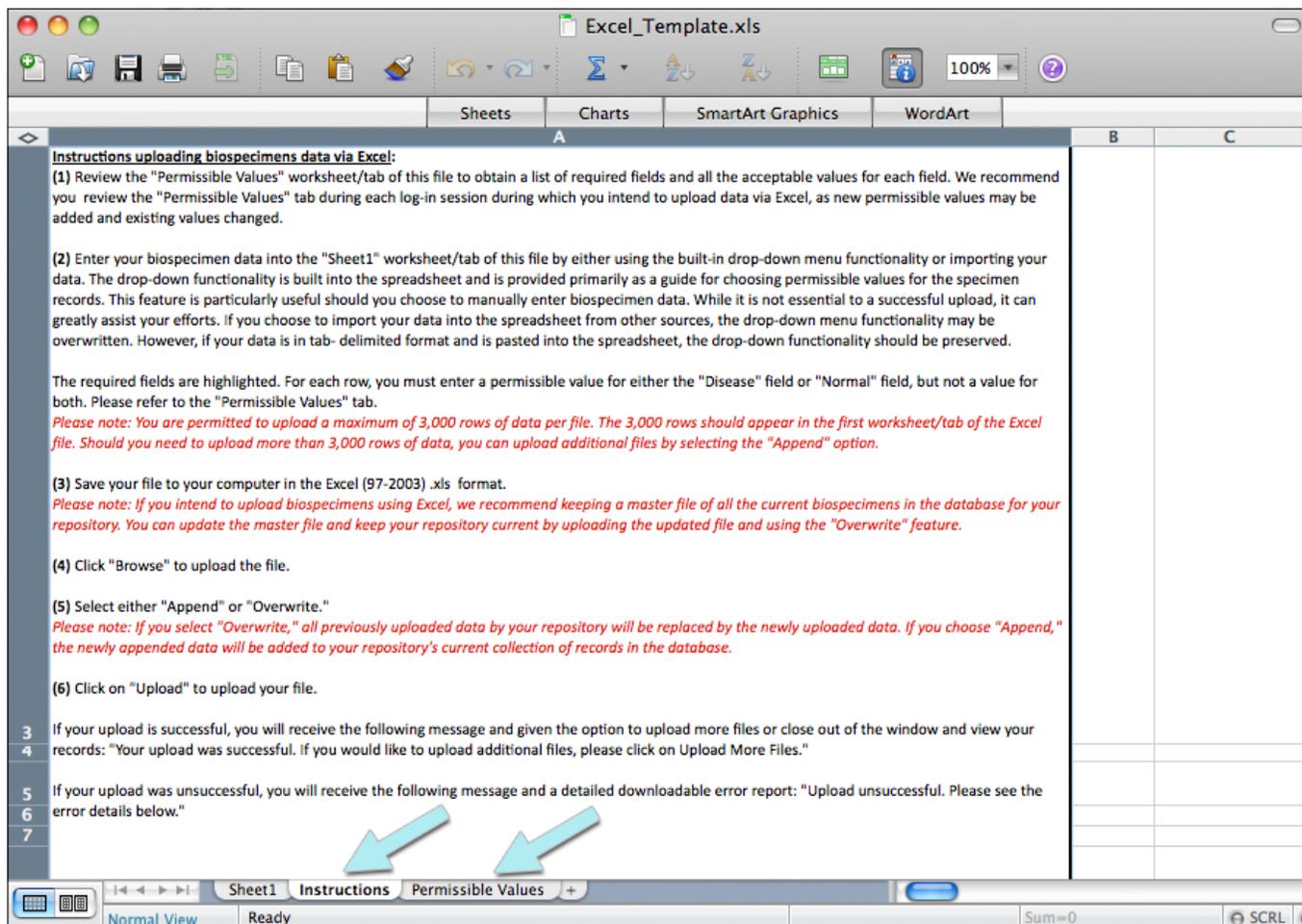


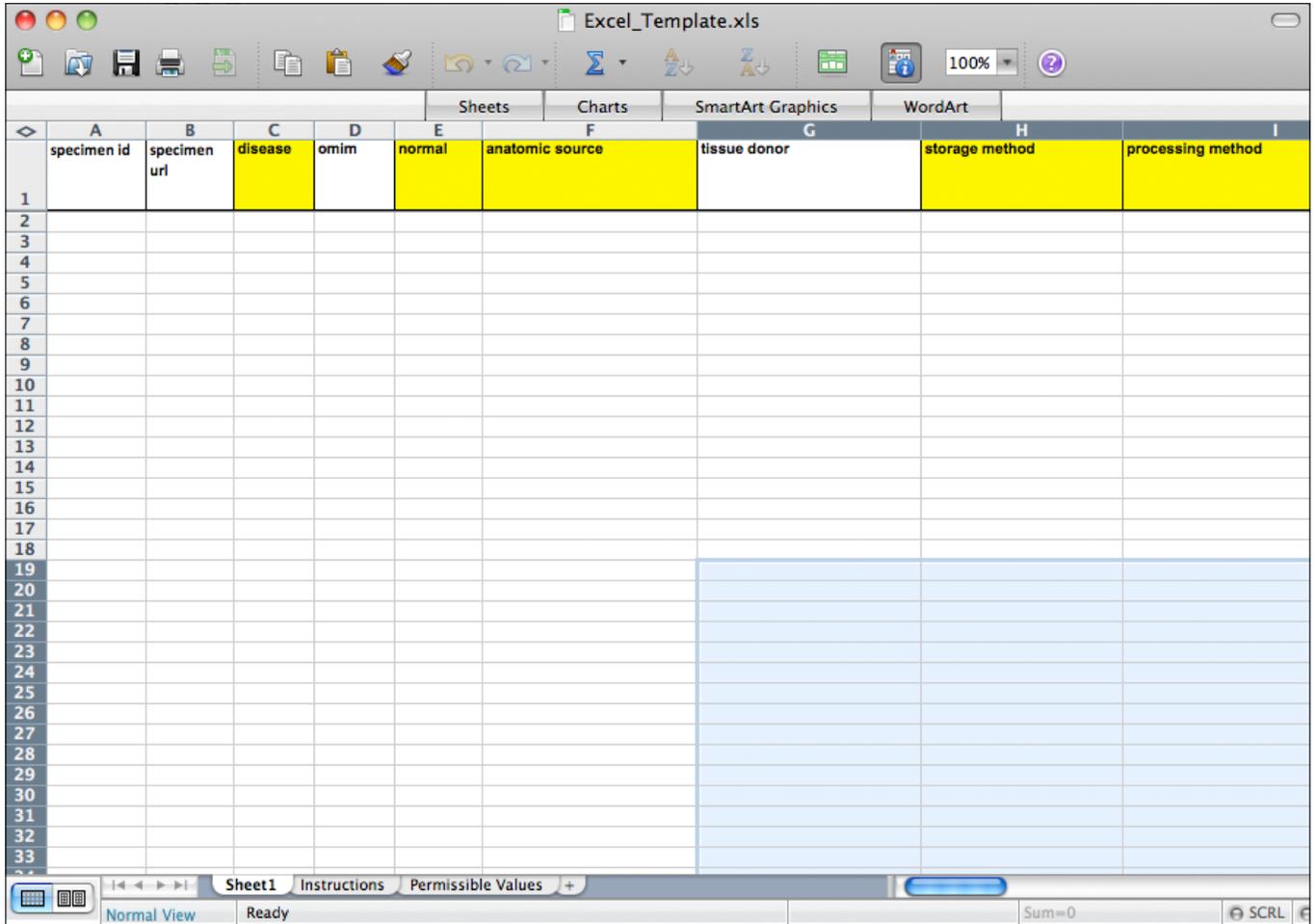
Figure 6. Excel Template Tabs for Instructions and Permissible Values



7. Enter your data to Sheet1 of the Excel file (see Figure 7).

*Please note:* The highlighted columns indicate required fields. A value is required for either the “Disease” field or “Normal” field.

**Figure 7.** Sheet 1 of Excel template



8. After saving your data, upload your file by selecting “Browse” (see Figure 5).

*Please note:* You will only be able to upload 1 file at a time with data in only 1 sheet and a maximum of 3,000 rows.

9. Once you have attached your file, select either “Overwrite” or “Append” (see Figure 5). Be sure to note the last date and time an Excel file was uploaded by your repository.

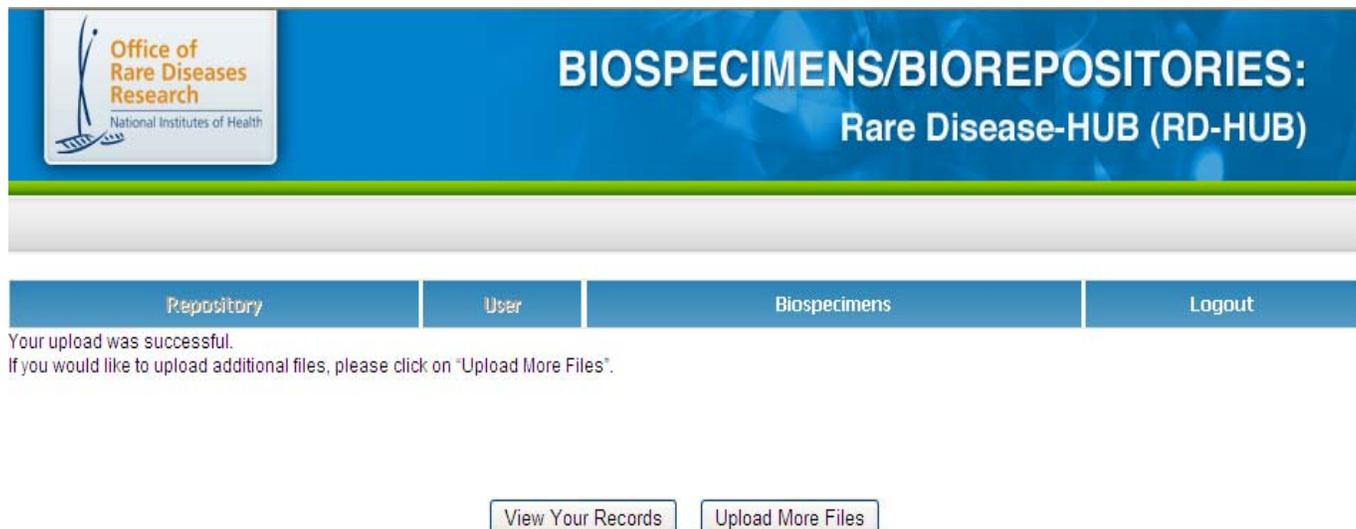
*Please note:* If you are uploading biospecimens data for the first time, you can select either “Overwrite” or “Append.”

10. Click “Upload” to upload your file (see Figure 5).

11. Review the results of your upload.

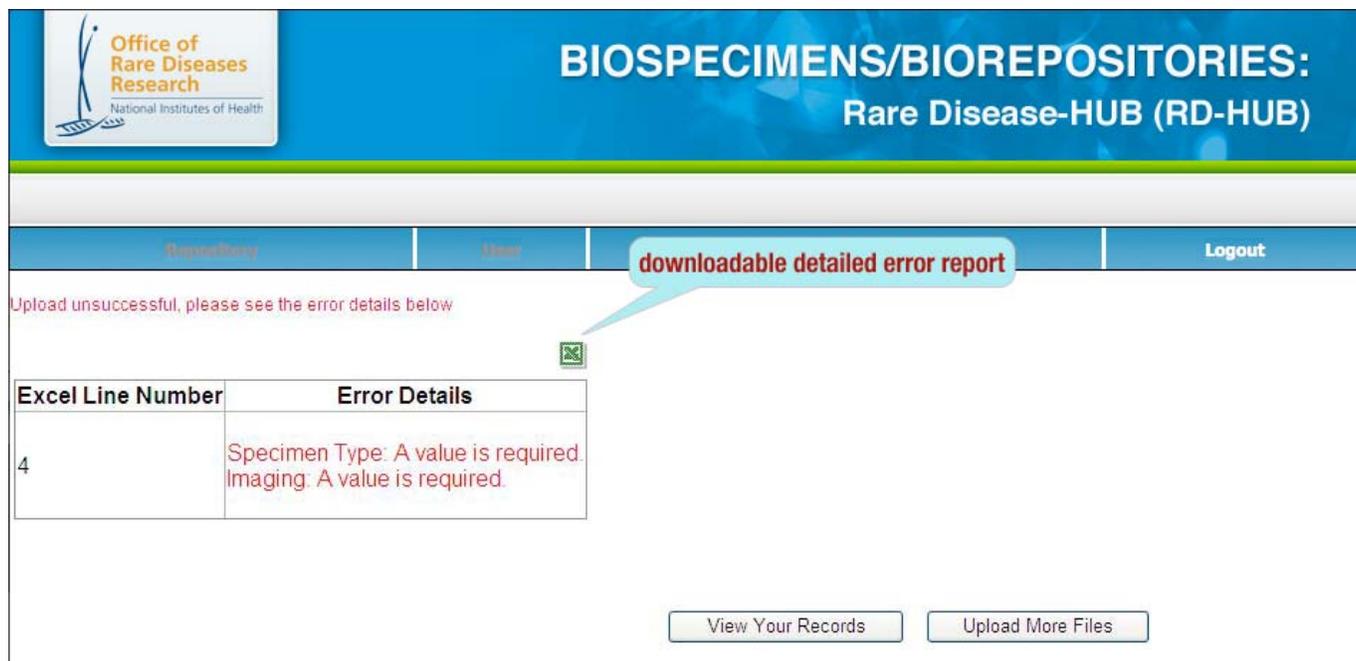
If your upload is successful, you will receive a message letting you know “your upload was successful”. Then, you will have the option to either close the window by clicking “View Your Records” or upload additional files by clicking “Upload More Files” (see Figure 8).

**Figure 8.** Successful upload message



If your upload was unsuccessful, a detailed downloadable error report will display. Please review the report and correct your errors. Once you have corrected the errors, you will have the option to re-upload the data via Excel and manually (see Figure 9).

**Figure 9.** Sample unsuccessful upload



- a. Correct the errors and re-upload all the data using the “Overwrite” functionality.  
*Please note: If you select “Overwrite” all the current biospecimens data for your repository will be replaced by the information contained in the file you are uploading.*
- b. Correct the errors and enter the corrected data using the manual upload functionality, which will append the biospecimen(s) data to the existing records in the database for your repository.

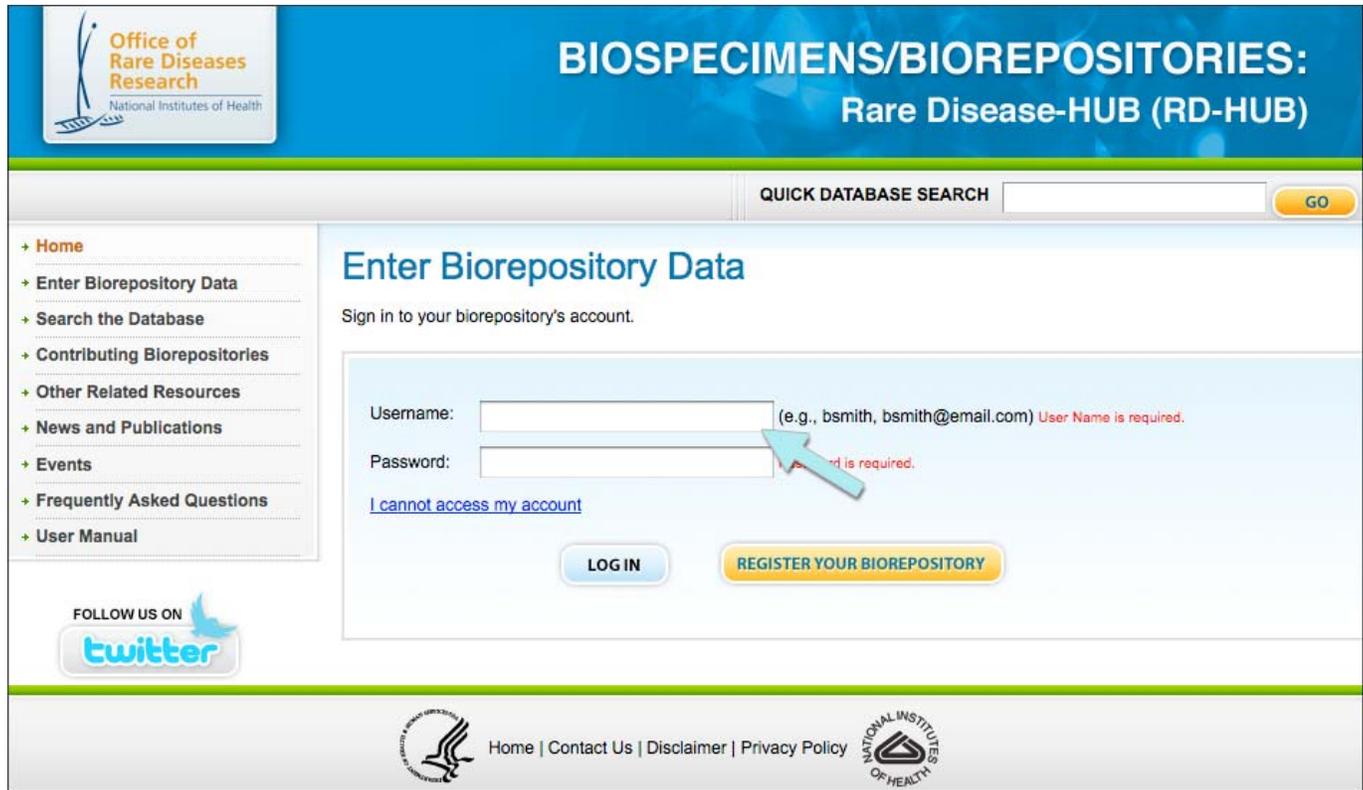
### Entering Biospecimens Data Manually

1. Log into your repository’s account by clicking “Enter Biorepository Data” on the left menu and entering your Username and Password (see Figures 10 and 11).

**Figure 10.** Screenshot of the left menu

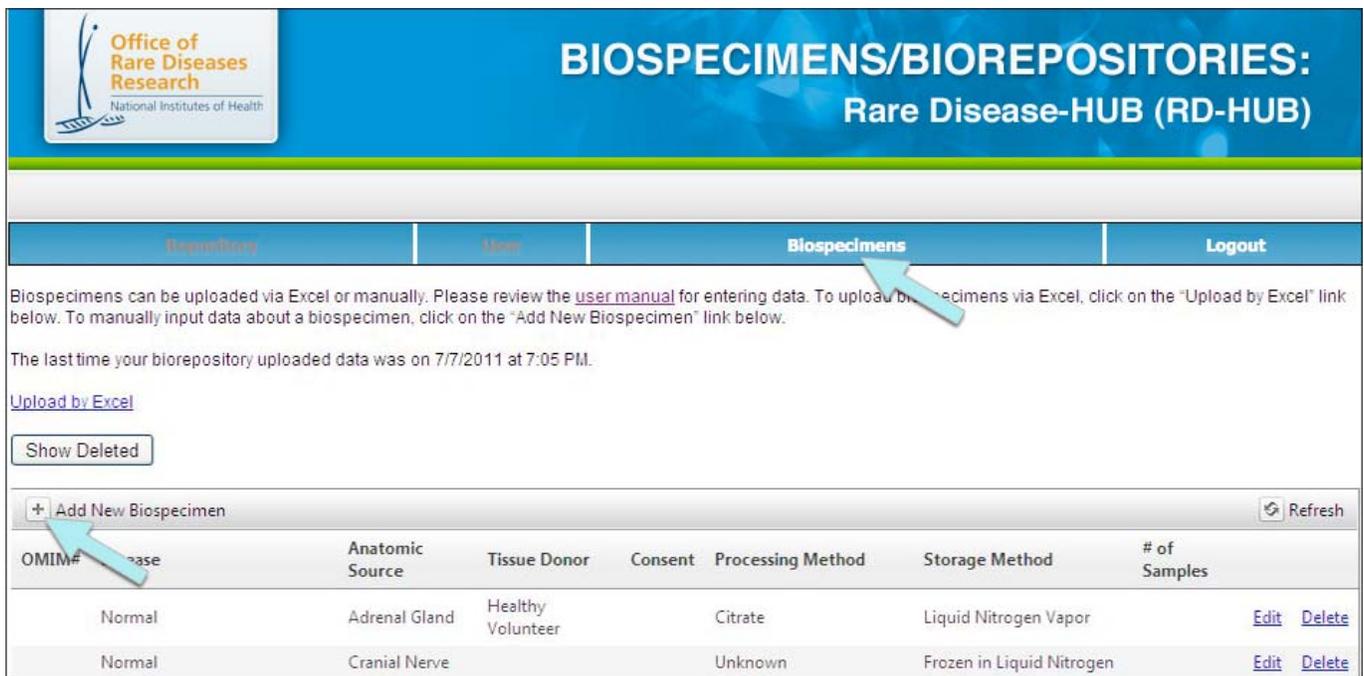
The screenshot displays the website for the Office of Rare Diseases Research, National Institutes of Health, titled "BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)". A "step 1" callout points to the "Enter Biorepository Data" option in the left sidebar menu. The main content area includes an "Overview" section with a welcome message and a "Goals" section with five numbered objectives. At the bottom, there are buttons for "Enter Biorepository Data" and "Search the Database", along with a "Fields required for entering biorepository data" link. The footer contains the NIH logo and navigation links.

**Figure 11.** Screenshot of log-in screen for accessing your biorepository’s account



2. Visit the *Biospecimens* tab (see Figure 12).
3. Click “Add new Biospecimen” (see Figure 12).

**Figure 12.** Biospecimens tab



4. Complete entering the information in the appropriate fields.

*Please note:* Some fields are required (**indicated by \***) when uploading biospecimen data (see Figure 13). In the case of the “Disease” and “Normal” fields, you only need to enter a value for one of the fields and not both.

When entering a disease name, use the “list of disease” link to locate the name of disease for the biospecimen (see Figures 13 and 14). You can copy and paste the name of the disease into the “Disease” field. If the disease of the biospecimen is not listed, you can manually add the name into the “Disease” field.

**Figure 13.** Manual form for uploading biospecimen data

**Office of Rare Diseases Research**  
National Institutes of Health

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

Repository | Users | **Biospecimens** | Logout

Biospecimens can be uploaded via Excel or manually. Please review the [user manual](#) for entering data. To upload biospecimens via Excel, click on the "Upload by Excel" link below. To manually input data about a biospecimen, click on the "Add New Biospecimen" link below.

[Upload by Excel](#)

Show Deleted

+ Add New Biospecimen Refresh

Instructions: Please complete the fields below. For detailed instructions, please refer to the [user manual](#) for entering data.

\* = Required

Disease: \* ([list of diseases](#))  -OR- Normal: \*  Yes  Unknown

OMIM Number  [Click here to search for an OMIM number](#)

Anatomic source: \*

Specimen Type: \*

Tissue Donor:

Storage Method: \*

Processing Method: \*

Type of Consent:

Imaging: \*

Number of Samples:

Ethnicity:

Race:

Gender:

Patient Age:

If you selected "Other" for any of the fields in this section, please use the comments field below to specify what "Other" means.

Comments:

Figure 14. "List of Diseases"

Please locate the name of the disease of the biospecimen you are uploading and copy and paste the disease name into the "Disease" field in the manual upload form.

# | [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](#)

#

10q partial trisomy  
11-beta-hydroxylase deficiency  
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  
18 Hydroxylase deficiency  
18p- syndrome  
1p36.33 deletion  
2,4-Dienoyl-CoA reductase deficiency  
21 hydroxylase deficiency  
22q11.2 deletion syndrome  
22q11.2 duplication syndrome  
22q13.3 deletion syndrome  
2-hydroxyethyl methacrylate sensitization  
2-Hydroxyglutaric aciduria  
2-methyl-3-hydroxybutyric aciduria  
2-Methylacetoacetyl CoA thiolase deficiency  
2-methylbutyryl-CoA dehydrogenase deficiency  
3 alpha methylcrotonyl-CoA carboxylase 2 deficiency  
3 Methylcrotonyl-CoA carboxylase 1 deficiency  
3 methylglutaconic aciduria type I  
3 methylglutaconic aciduria type IV  
3 methylglutaconic aciduria type V  
3-@BETA-HYDROXYSTEROID DEHYDROGENASE, TYPE II, DEFICIENCY OF  
3-@HYDROXY-3-METHYLGLUTARYL-CoA LYASE DEFICIENCY  
3-@METHYLCROTONYL-CoA CARBOXYLASE 1 DEFICIENCY  
3-@METHYLCROTONYL-CoA CARBOXYLASE 2 DEFICIENCY

5. Click “Save” (see Figure 15).
6. If you desire to enter additional biospecimen records, repeat Steps 3–5.

**Figure 15.** Save feature on manual upload form

Race:

Gender:

Patient Age:

If you selected “Other” for any of the fields in this section, please use the comments field below to specify what “Other” means.

Comments:

**Cost per Sample**

Is there a cost associated with the specimen?  Yes  No

Is there a cost associated with the shipping and handling of the specimen?  Yes  No

**Specimen Annotation**

Specimen ID:

Specimen URL:

Is there histopathologic information?  Yes  No

Is there lab data?  Yes  No

Are there matched specimens?  Yes  No

Are genetic testing results available?  Yes  No  Unknown

**Patient Information**

Is there additional information regarding patient demographic?  Yes  No

Is there medical history information available?  Yes  No

Is there family history information available?  Yes  No

Are participants available for follow-up?  Yes  No  Unknown

Is there treatment information available?  Yes  No



## Editing Biospecimens Data

Samples can be edited either via Excel or manually.

*Please note:* If you edit just one of your records then the date/time stamp of when your repository was last modified will be updated

### Edit via Excel

Please refer to the *Uploading via Excel* section of this user manual for detailed instructions.

### Edit Manually Select

To manually edit a biospecimen record, perform the steps below.

1. Log into your repository's account by clicking on "Enter Biorepository Data" on the left menu and entering your Username and Password (see Figures 16 and 17).

Figure 16. Screenshot of the left menu

The screenshot displays the website interface for the Office of Rare Diseases Research, National Institutes of Health. The header includes the logo and the title "BIOSPECIMENS/BIOREPOSITORIES: Rare Disease-HUB (RD-HUB)". A search bar is located at the top right. The left navigation menu lists several options, with "Enter Biorepository Data" highlighted by a blue arrow. 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", and a link for "Fields required for entering biorepository data".

Office of Rare Diseases Research  
National Institutes of Health

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

Overview

Welcome to the Biospecimens/Biorepositories Website: Rare Disease-HUB (RD-HUB) of the Office of Rare Diseases Research (ORDR). This Website contains a searchable database of biospecimens collected, stored, and distributed by biorepositories in the United States and around the globe.

Goals

1. To help and assist interested parties and investigators search, locate, and identify desired biospecimens needed for their research.
2. To facilitate collaboration and sharing of material and data among investigators across the globe.
3. To accelerate research to facilitate the discovery of new treatments, therapeutics and eventually cures for rare diseases as well as common diseases.
4. To identify, locate and increase the awareness of existing biorepositories across the globe.
5. To link the RD-HUB to the Global Rare Diseases Registry (GRDR). To learn more about the GRDR, please visit [http://rarediseases.info.nih.gov/Patient\\_Registries](http://rarediseases.info.nih.gov/Patient_Registries).

FOLLOW US ON  
twitter

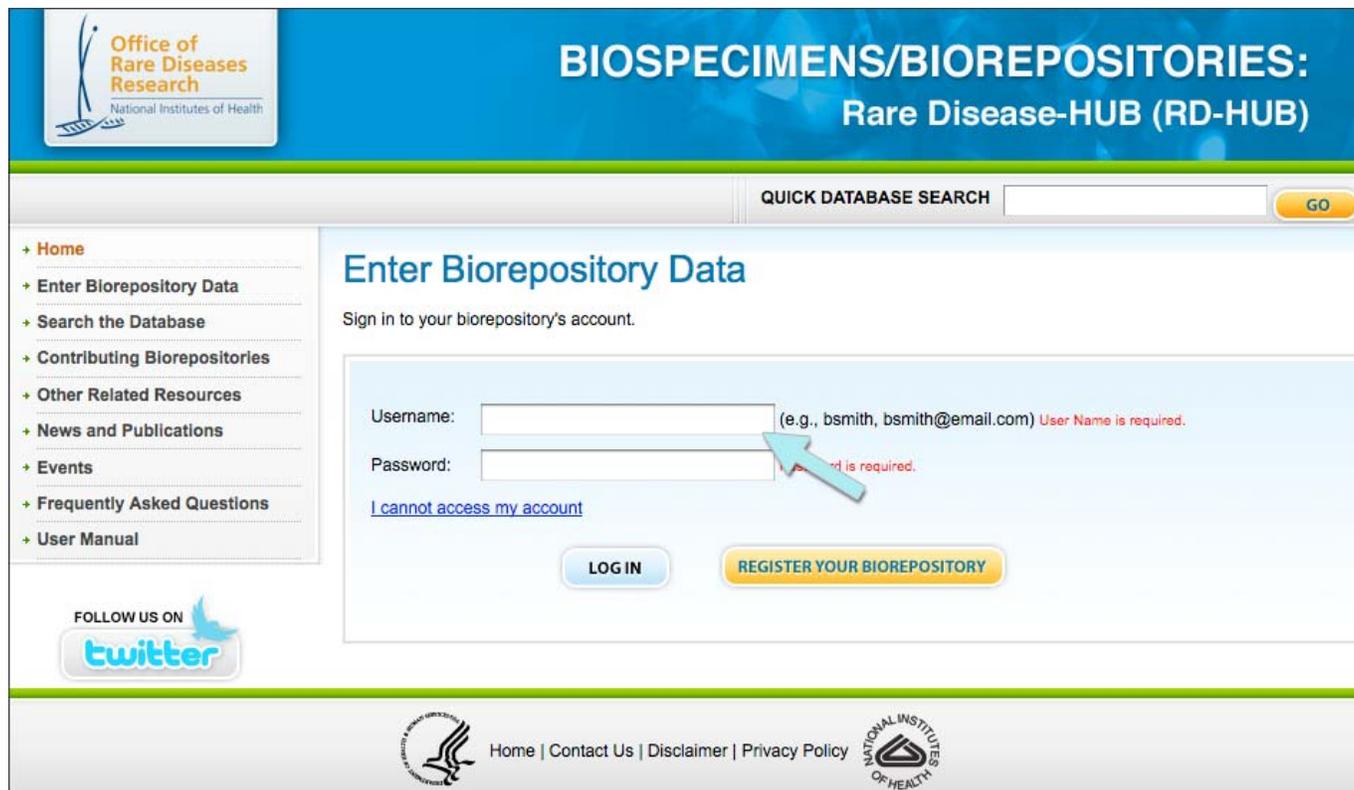
Enter Biorepository Data Search the Database

Fields required for entering biorepository data

Home | Contact Us | Disclaimer | Privacy Policy

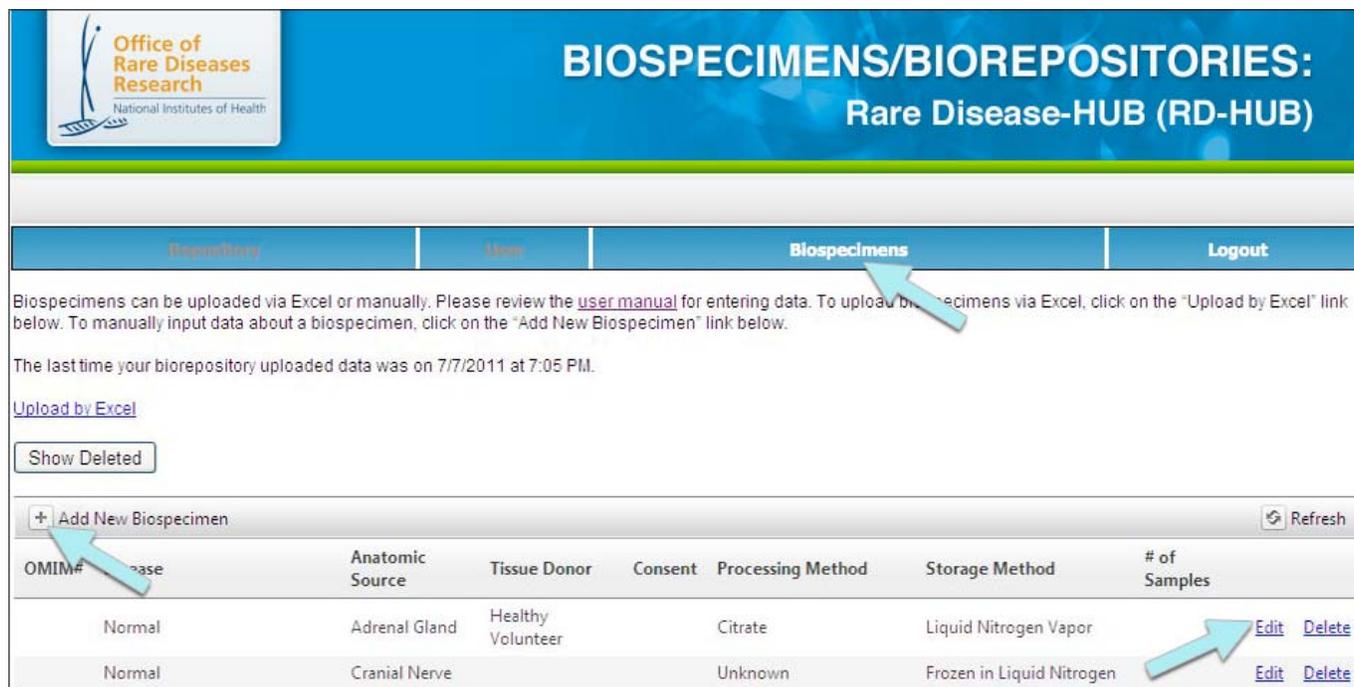
NATIONAL INSTITUTES OF HEALTH

Figure 17. Screenshot of log-in screen for accessing your biorepository's account



2. Visit the *Biospecimens* tab (see Figure 18).
3. Click “Edit” next to the biospecimen you would like to edit (see Figure 18).

Figure 18. Biospecimens tab



4. Make your edits.
5. Click “Save” (see Figure 19).
6. Repeat Steps 3–5 for each biospecimen you would like to edit.

**Figure 19.** Save button for manual upload form

Race:

Gender:

Patient Age:

If you selected “Other” for any of the fields in this section, please use the comments field below to specify what “Other” means.

Comments:

**Cost per Sample**

Is there a cost associated with the specimen?  Yes  No

Is there a cost associated with the shipping and handling of the specimen?  Yes  No

**Specimen Annotation**

Specimen ID:

Specimen URL:

Is there histopathologic information?  Yes  No

Is there lab data?  Yes  No

Are there matched specimens?  Yes  No

Are genetic testing results available?  Yes  No  Unknown

**Patient Information**

Is there additional information regarding patient demographic?  Yes  No

Is there medical history information available?  Yes  No

Is there family history information available?  Yes  No

Are participants available for follow-up?  Yes  No  Unknown

Is there treatment information available?  Yes  No



## ***Deleting Biospecimens Data***

### **All Samples**

To delete all the samples, please [Yaffa.Rubinstein@nih.gov](mailto:Yaffa.Rubinstein@nih.gov).

### **Select Samples**

To delete selected samples, perform the following steps:

1. Log into your biorepository's account.
2. Click the *Biospecimens* tab.
3. Click "delete" next to the biospecimen you would like to delete.
4. Click "OK"
5. Repeat Steps 3–4 for each biospecimen you would like to delete.

## **Forgotten Log-in Credentials**

If you have forgotten your log-in credentials, you can request they be sent to you by completing the online form available at the link below.

If you continue to experience technical difficulties accessing your repository's account, please send an e-mail to Yaffa Rubinstein, Ph.D., at [Yaffa.Rubinstein@nih.gov](mailto:Yaffa.Rubinstein@nih.gov).

## **Technical Difficulties**

If you are experiencing technical difficulties with RD-HUB, please contact Yaffa Rubinstein, Ph.D., at [Yaffa.Rubinstein@nih.gov](mailto:Yaffa.Rubinstein@nih.gov).