User Manual:

Human Biospecimens/ Biorepositories Database Data Entry

Table of Contents

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.

Figure 1. Online registration form for new repositories

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.

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.

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.

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

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

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

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
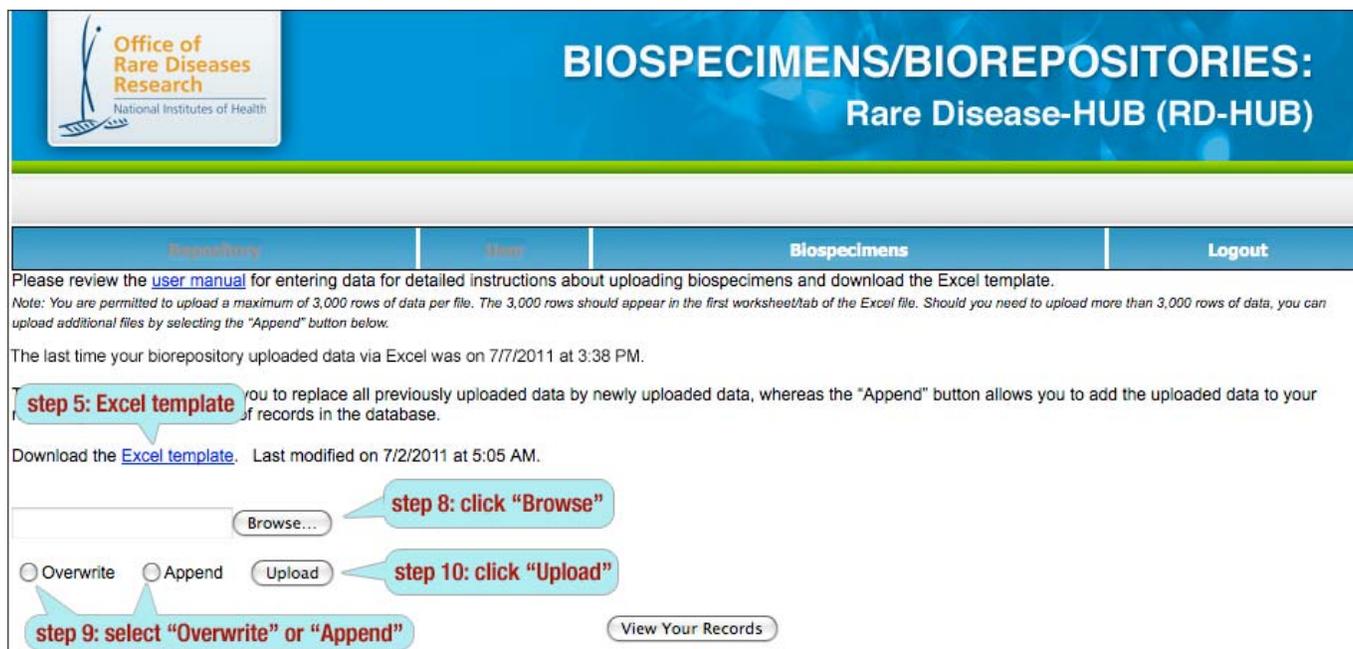
Figure 6. Excel Template Tabs for Instructions and Permissible Values
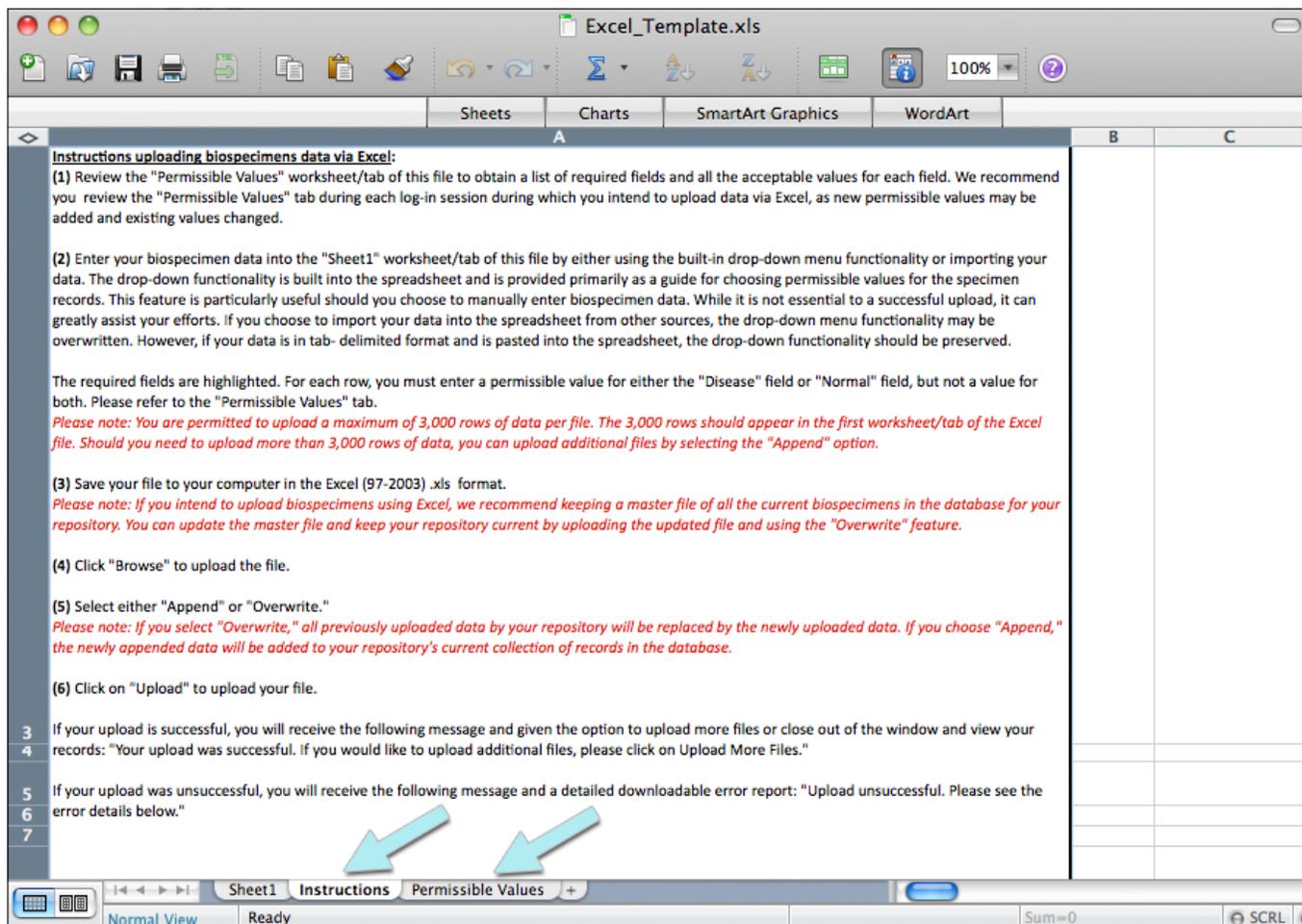
7. Enter your data to Sheet1 of the Excel file (see Figure 7).

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
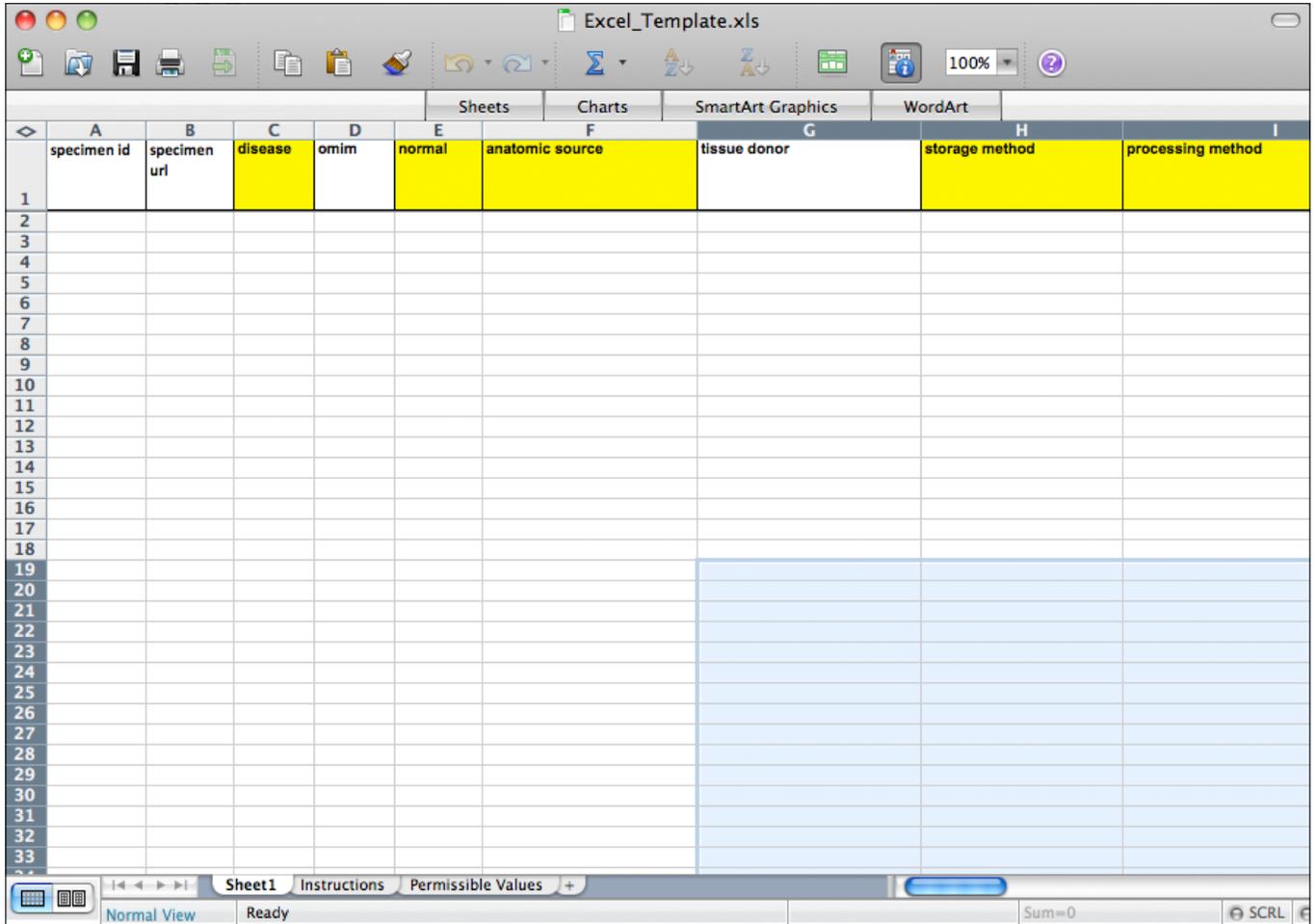
8. After saving your data, upload your file by selecting "Browse" (see Figure 5).
Please note: You will only be able to upload 1 file at a time with data in only 1 sheet and a maximum of 3,000 rows.

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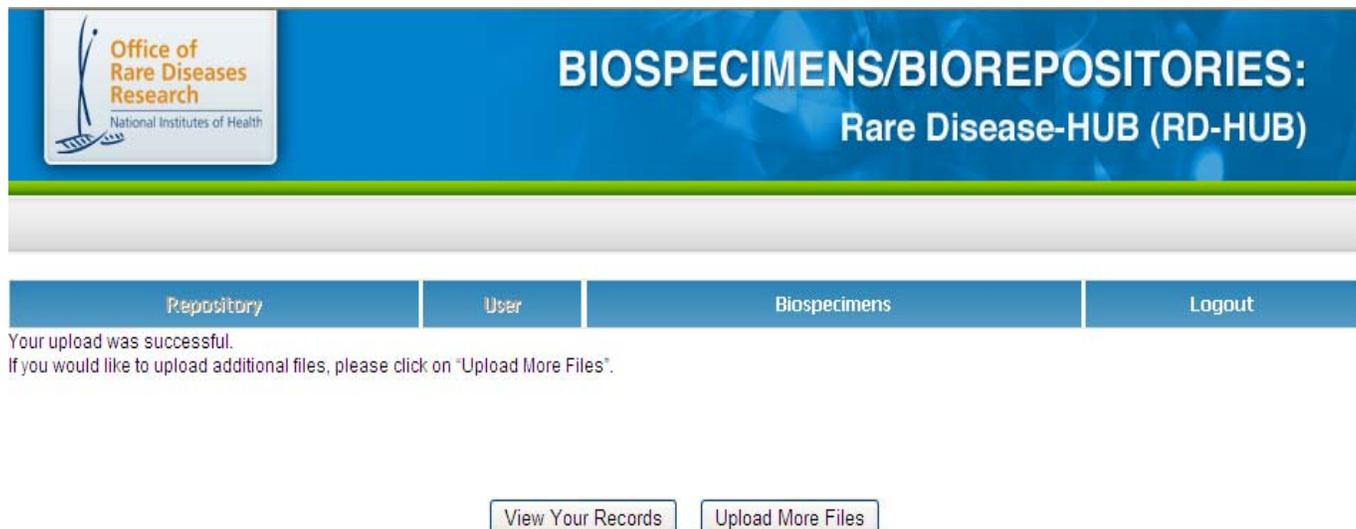
If your upload was unsuccessful, a detailed downloadable error report will display. Please review the report and correct your errors. Once you have corrected the errors, you will have the option to re-upload the data via Excel and manually (see Figure 9).

Figure 9. Sample unsuccessful upload
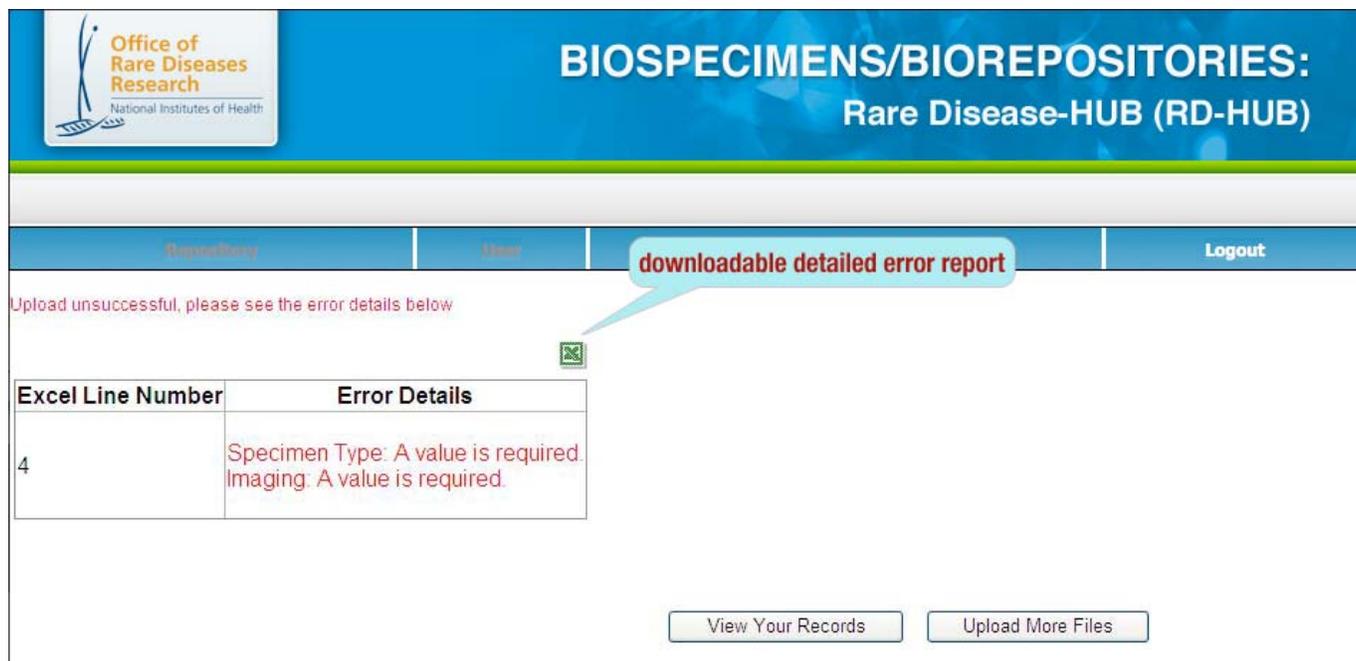
a. Correct the errors and re-upload all the data using the "Overwrite" functionality.
   Please note: If you select "Overwrite" all the current biospecimens data for your repository will be replaced by the information contained in the file you are uploading.

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

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
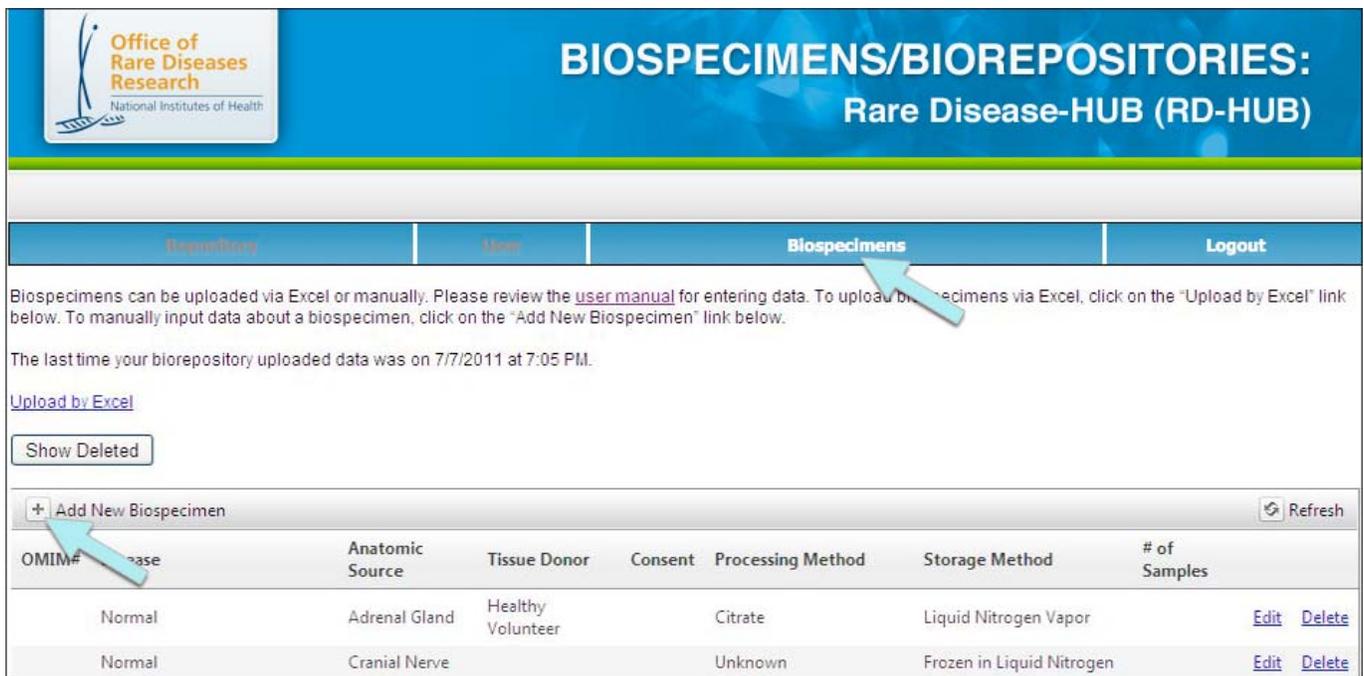
4. Complete entering the information in the appropriate fields.

   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

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

15

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

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

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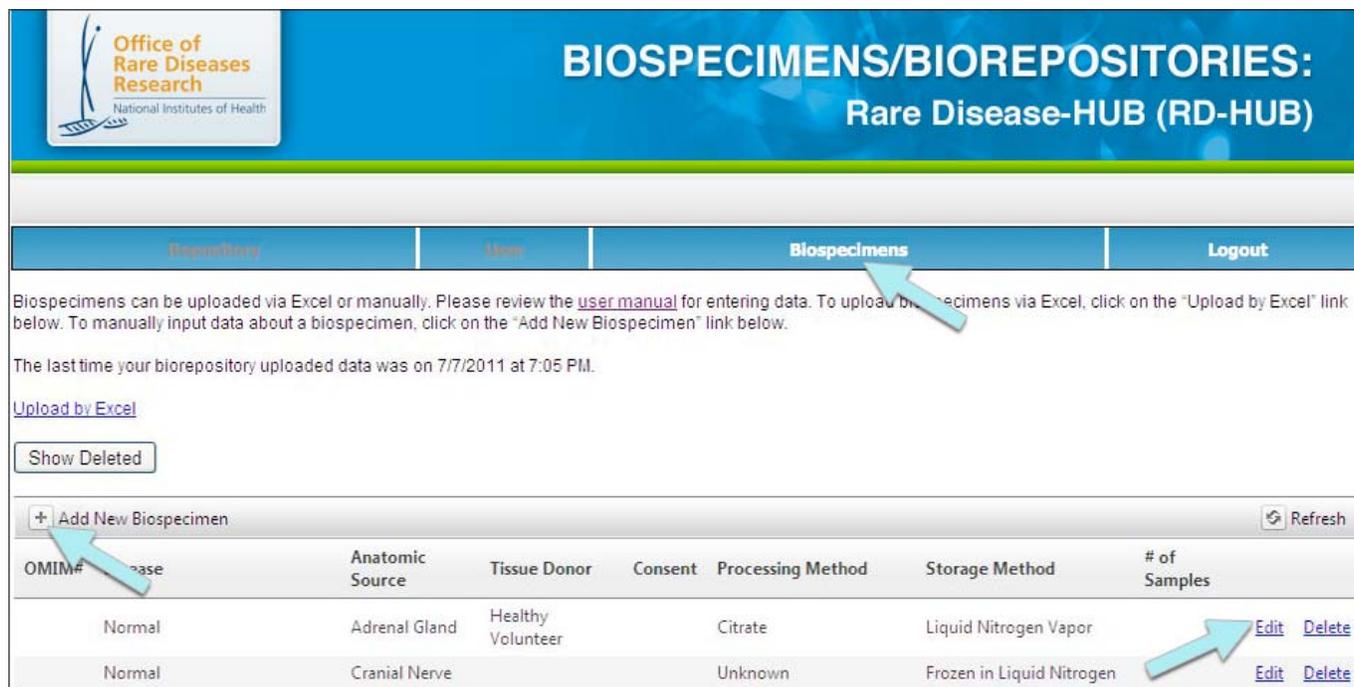
4. Make your edits.
5. Click "Save" (see Figure 19).
6. Repeat Steps 3–5 for each biospecimen you would like to edit.

Figure 19. Save button for manual upload form

Deleting Biospecimens Data

All Samples

To delete all the samples, please 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.

Technical Difficulties

If you are experiencing technical difficulties with RD-HUB, please contact Yaffa Rubinstein, Ph.D., at Yaffa.Rubinstein@nih.gov.