Submitter's Guide

NINDS Human Genetics Resource Center

at the

Coriell Institute for Medical Research

The NINDS Human Genetics Resource Center at the Coriell Institute for Medical Research

Mission

The National Institute of Neurological Disorders and Stroke (NINDS) is committed to gene discovery as a strategy for identifying the genetic causes and correlates of nervous system disorders. The NINDS Human Genetics Resource Center at the Coriell Institute, also known as the NINDS Repository, receives blood samples and clinical data and prepares DNA and cell lines for distribution to promote neurogenetics research. The NINDS Repository is HIPAA compliant and has a certificate of confidentiality.

Neither NIH/NINDS nor Coriell make a profit from the distribution of samples from the NINDS Repository. Please see the website's link for publications citing the Repository.
http://ccr.coriell.org/Sections/Collections/NINDS/Publns.aspx?PgId=490&coll=ND

This mission of the NINDS Human Genetics Resource Center is to provide:

- genetics support for scientists investigating pathogenesis in the central and peripheral nervous systems through submissions and distribution
- information support for patients, families, and advocates concerned with the living-side of neurological disease and stroke

Who Can Submit Samples to the NINDS Repository?

There are two ways to apply to become a submitter to the NINDS Repository: apply to become a Repository "Investigator", or alternatively, apply to become a Repository "Collaborator" by identifying a currently-approved Repository Investigator. All applications to submit samples to the NINDS Repository require annual approval by NINDS. Annual approval is in lock-step with local IRB approval of the submitting project and consent. Typically, approval is restricted to those with projects funded by NINDS.

Application Process to Bank Samples & Data in the NINDS Repository

1. The first step for any Investigator is to contact the NINDS Program Director for their grant or grant application; their Program Director then petitions the NINDS Repository Project Officer to endorse the Investigator's banking efforts with the NINDS Repository.
2. Each applicant must then submit the following documents:
    - Completed Approval and Tracking Data form (i.e. the application). These forms can be downloaded from our website: http://ccr.coriell.org/Sections/Collections/NINDS/Depositing.aspx?PgId=153&coll=ND

- Blank copy of the IRB-approved consent that will be used to collect samples. IRB approval and expiration dates must be clearly indicated on the consent document, or in a letter of approval from your IRB. Minimum consent requirements, as well as a model informed consent, can be found on our website: http://ccr.coriell.org/Sections/Collections/NINDS/Depositing.aspx?PgI d=153&coll=ND

If an Investigator or Collaborator is a first-time submitter to the Repository it is highly recommended that a copy of the consent form is sent to one of the Project Managers for review prior to review by the local IRB. This will avoid rejection by the Repository and re-submission to the local IRB which can delay sample banking.

Applications should be submitted to an NINDS Repository Project Manager via email (ninds@coriell.org) or fax (856-757-9737). Documents will be reviewed by the NINDS Repository Principal Investigator and Project Officer, and you will be informed of approval via email. Approval is subject to NINDS funding and programmatic considerations.

Annual Renewal of Approval

Each submitter is required to renew approval to submit samples on a yearly basis. Automatic e-mail reminders to submit an application for renewal are sent to submitters starting 90 days prior to approval expiration. To renew, submitters will be required to submit an updated Approval and Tracking Data Form and current IRB-approved consent/s.

Project Organization

The NINDS Repository offers significant flexibility in organization of your project in terms of how you interact with the Repository. The roles are as follows:

Investigator: Leader of the banking efforts; usually the Principal Investigator of the NINDS-funded project that is banking samples. Investigators receive submitter benefits: back-in-kind DNA and discounted pricing ("discount chits") on purchases.

Collaborator: Associated with an Investigator. Collaborators submit samples under their own or under their Investigator's IRB-approved consent. Collaborators do not directly receive back-in-kind samples or discount pricing.

Projects are organized in one of two ways:

- Investigators without Collaborators
- Groups. Groups include one or more Investigators, and may or may not include Collaborators (if there is only 1 Investigator, there must be at least 1 Collaborator to constitute a Group).

Investigators and Collaborators both represent sites that collect blood samples and data for submission to the Repository; however, on rare occasions, a large project may have an

Investigator that only oversees the project and does not submit samples. Diagrams of these organizations are listed below. Note that the Group example shown is typical. There are many other possible Groups, although the basic hierarchical organization remains the same.

Example A: Single Investigator, no Group

Investigator

→ Coordinator

Example B: Typical Group consisting of one Investigator and one or multiple Collaborators

Investigator

→ Coordinator

→Collaborator A

→ Coordinator

→Collaborator B

→Coordinator

Submitter Benefits

DNA samples back-in-kind: Investigators will receive 20 µg of DNA free of charge from each blood sample they submit.

Discount pricing: For each sample an Investigator submits to the NINDS Repository, they will receive one discounted purchase credit (discount "chit") which can be used for any sample available in the NINDS Repository catalog.

It is **REQUIRED** that any individual other than the Investigator or one of their approved Collaborators who is designated to receive back-in-kind samples have a current NINDS Repository MTA Form on file with the Customer Service Department at Coriell. The MTA Form can be found on our website: http://ccr.coriell.org/Sections/Collections/NINDS/Ordering.aspx?PgId=152&coll=ND

NINDS Repository Commitment to Submitters

- Provide support for submitting samples and data
    - Instruction
    - Supplies
    - Trouble shooting

- Reminders to submit clinical data and renew submitter approval

Submitter Commitments to the NINDS Repository

- Updated Approvals
- Adequate blood submissions
  - Safe and appropriate blood shipment
  - Volume
  - Transit time/Age of sample (not greater than 5 days old)
  - Paperwork (Fully completed Submission Form)
- Timely submission of complete clinical data

Using Queue

What is Queue?

Queue is an online database that you will use for routine interaction with the NINDS Repository, such as ordering collection kits, entering clinical data, and viewing data associated with your submissions.

Who Has Access?

Each Coordinator will be provided with a Queue user account upon approval to submit samples; access may also be granted to Investigators and Collaborators upon request.

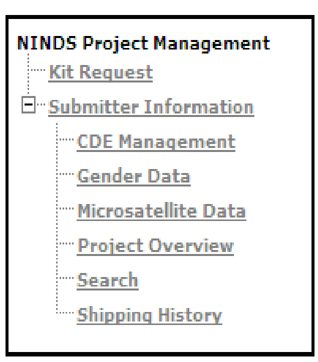
Investigators and their coordinators are able to view data associated with submissions from all Collaborators submitting samples for their project.

Collaborators and their Coordinators will only be able to view data associated with submissions from their own site.

Getting Started

Log in to Queue with your provided username and password at: https://queue.coriell.org/q/.

Under the Contracts link in the upper left-hand corner of the screen, select NINDS Project Management. You will see the menu listed below:



Steps to Submit Samples to the NINDS Repository

The first thing you will need to do is order sample collection and shipping kits. **IMPORTANT:** Please be sure to allow two-week lead-time when requesting supplies.

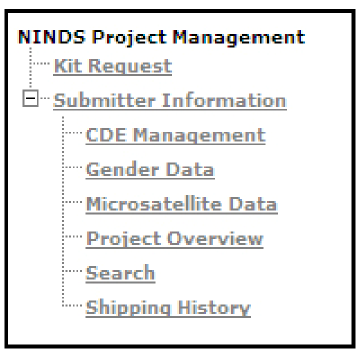
What is a Kit?

The NINDS Repository provides kits containing supplies for collecting and shipping blood samples. Each individual kit contains the following supplies:

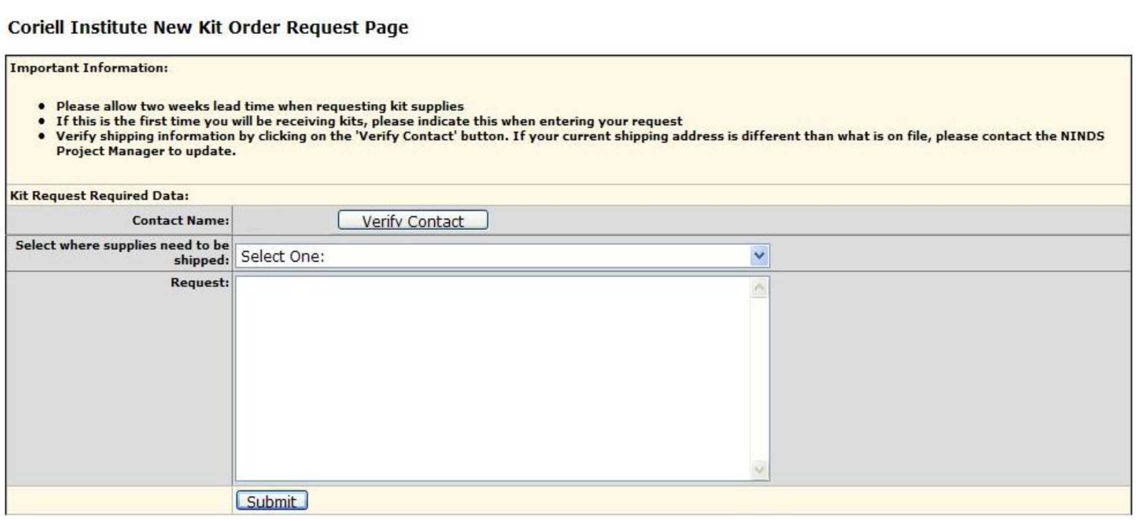
- Blood collection tubes
  - 10 ml ACD tubes, unless a pediatric kit is requested, in which case 5ml EDTA tubes will be provided.
- Packaging materials
- NINDS Sample Submission and Shipping Form
- Blood collection and shipping protocol
- Styrofoam box and cardboard shipping carton
- Warning label packet
- Pre-paid FedEx shipping label and pouch

How to Order Kits

- Log into Queue.
- Click the Contracts link in the upper left-hand corner of the screen, and the following menu will be displayed



- Click the Kit Request link. The following screen will be displayed:



- Use the drop-down menu to select where the supplies should be shipped. If the shipping address-(es) on the list is not the one you need, contact a NINDS Project Manager at ninds@coriell.org.
- Enter any special requests or notes in the Request field.
    - If you need pediatric kits please make a note of it here.
- Individual kit components can be ordered instead of complete kits (such as extra blood tubes) by entering your request in the Request field.
- Click the Submit button.

You will be shipped an order of 8 kits unless otherwise specified (there are 8 kits per case). Each kit contains enough supplies to collect and ship samples from 3 subjects. Double kits, containing supplies for 6 subjects, are also available upon request.

You should allow at least two weeks for kit orders to be processed and delivered.

Collecting and Shipping Samples

Once you receive your supplies, you can begin sample collection.

Important
Please make every effort to avoid submitting duplicate blood samples. We recommend that you query subjects about previous participation in the NINDS Repository as part of your interview process.

- Draw 2 tubes of blood per subject.
- **Fill each tube to the top.** Tubes that are less than half full (4 ml) should not be shipped, as these tubes will not be accepted for processing. **Multiple low-volume tubes cannot be combined.**
- Always keep blood samples at room temperature. **Do NOT refrigerate or freeze!**

- Clearly label each tube with the subject ID and date of collection.
- Seal tubes with the tape provided.
- Insert each tube into the bubble wrap pouch.
- Place the bubble pouch and absorbent sheet into the plastic biohazard bag.
- Seal plastic bag inside of paper biohazard envelope.
- Fill out the NINDS Sample Submission and Shipping Form.
- Package the samples and the completed submission form into the shipping carton. Incomplete forms could delay the processing of samples.
- Samples from multiple subjects can be included in a single shipping carton.

- What **NOT** to include:
    - Paper CDEs
    - Consent forms
    - Dry ice or ice packs
    - Invoices, laboratory documents, or any other document with identifying patient information.
- Affix warning labels and FedEx label to outside of shipping carton.
- Samples should be shipped Priority Overnight (next business morning) to arrive at Coriell on Monday through Friday.
- Notify a NINDS Project Manager of shipment by fax (856-966-5067) or email (ninds@coriell.org). Include the FedEx tracking number, submitter's name, and the number of samples to be shipped.
- **IMPORTANT NOTE REGARDING LARGE SAMPLE SHIPMENTS**: When shipping 20 or more samples in one day, you must provide at least 24 hours notification of shipment.

Important
Please note that if a *completed* submission form is not included with the shipped samples this may cause a delay in the processing of those samples.

Sample ID Numbers

Each study assigns their own Subject IDs to the blood samples they collect. Once a blood sample is received at Coriell, a NINDS ID is also assigned to the sample*. The Subject ID is captured in the database along with the assigned NINDS ID. However, the assigned NINDS ID is the primary identification number used in the sample handling. It represents the catalog number that will be used when the DNA and/or cell line are created from the blood specimen. You can use either ID to access data in Queue.

*If you have entered a CDE in Queue before the shipping the blood sample, the NINDS ID will not appear until the sample arrives at Coriell.

Important
ALWAYS use the exact same format for a Subject ID when labeling tubes, paperwork, and entering data in Queue. Even a small difference such as an extra/missing space, hyphen, letter, number or punctuation will prevent Queue from matching up samples with their associated data. If you notice a discrepancy of this type, please contact a NINDS Project Manager at ninds@coriell.org for assistance.

Entering Clinical Data

COMPLETE clinical data must be submitted for every subject whose sample is sent to the NINDS Repository. If clinical data is not complete, you will not receive back-in-kind DNA. Clinical data is to be submitted electronically through Queue, unless other arrangements have been approved by the NINDS PI.

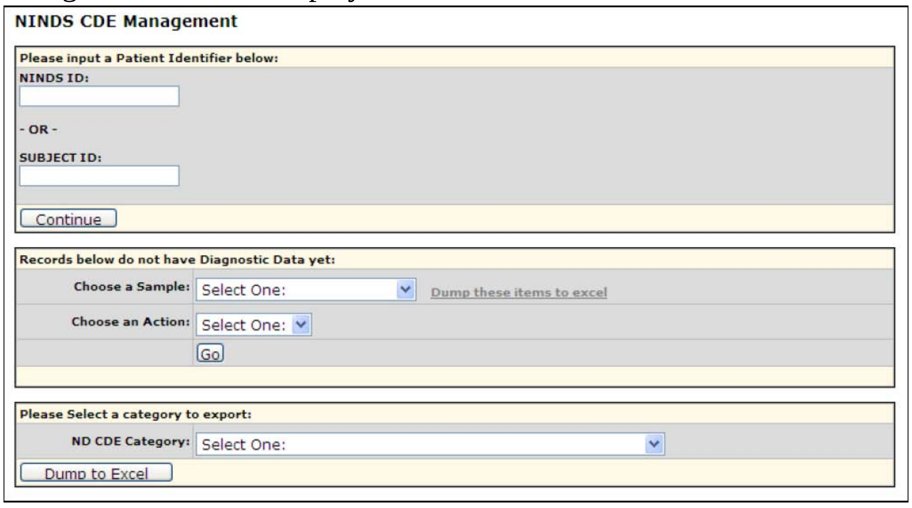
Paper versions of the required Clinical Data Element (CDE) forms can be downloaded from our website: http://ccr.coriell.org/Sections/Collections/NINDS/ClinicalDataForms.aspx?PgId=148&co ll=ND

We will not accept as controls any individuals who themselves, or whose first degree relatives, have stroke, epilepsy, Parkinsons, or dementia, as this will prohibit our pooling of controls with other NIH collections. In some cases, those with related disorders to one of our collections may also be excluded (for example, a person with a TIA or carotid stenosis would not be considered a good control for Parkinson's, since, stroke is one of our target collections; likewise, a subject with a parent or sibling with Alzheimer's disease (AD) would not be a good control, since we are collecting Parkinsons and ALS which may have a biological relationship to AD). If you are using subjects with a neurological disorder such as stroke, epilepsy, Parkinson's, as controls for your particular study, please do not fill out the control CDEs for that submission, but fill out the correct disease CDE for that disorder. That will allow us to accept them in most circumstances.

How to Create a New CDE

- Log into Queue.
- Click the Contracts link in the upper left-hand corner of the screen, and the following menu will be displayed:

- Click the CDE Management link.
- The following screen will be displayed:



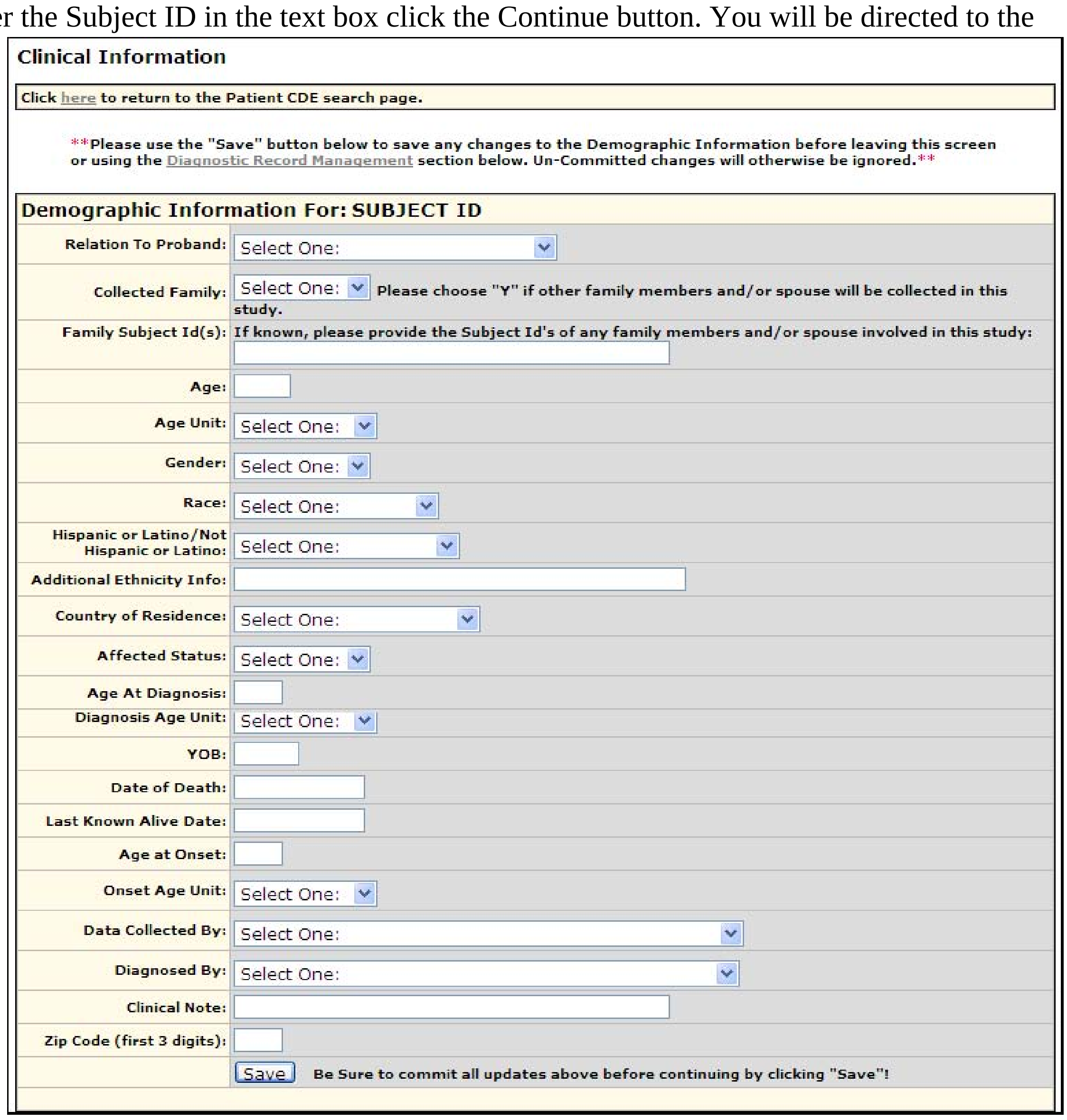
NINDS CDE Management

Please input a Patient Identifier below:
NINDS ID:
- OR -
SUBJECT ID:
Continue

Records below do not have Diagnostic Data yet:
Choose a Sample: Select One: Dump these items to excel
Choose an Action: Select One:
Go

Please Select a category to export:
ND CDE Category: Select One:
Dump to Excel

Step 1: Enter the Subject ID in the text box click the Continue button. You will be directed to the next screen:



Clinical Information

Click here to return to the Patient CDE search page.

Please use the "Save" button below to save any changes to the Demographic Information before leaving this screen or using the Diagnostic Record Management section below. Un-Committed changes will otherwise be ignored.

Demographic Information For: SUBJECT ID

Relation To Proband:	Select One:
Collected Family:	Select One: Please choose "Y" if other family members and/or spouse will be collected in this study.
Family Subject Id(s):	If known, please provide the Subject Id's of any family members and/or spouse involved in this study:
Age:	
Age Unit:	Select One:
Gender:	Select One:
Race:	Select One:
Hispanic or Latino/Not Hispanic or Latino:	Select One:
Additional Ethnicity Info:	
Country of Residence:	Select One:
Affected Status:	Select One:
Age At Diagnosis:	
Diagnosis Age Unit:	Select One:
YOB:	
Date of Death:	
Last Known Alive Date:	
Age at Onset:	
Onset Age Unit:	Select One:
Data Collected By:	Select One:
Diagnosed By:	Select One:
Clinical Note:	
Zip Code (first 3 digits):	
	Save Be Sure to commit all updates above before continuing by clicking "Save"!

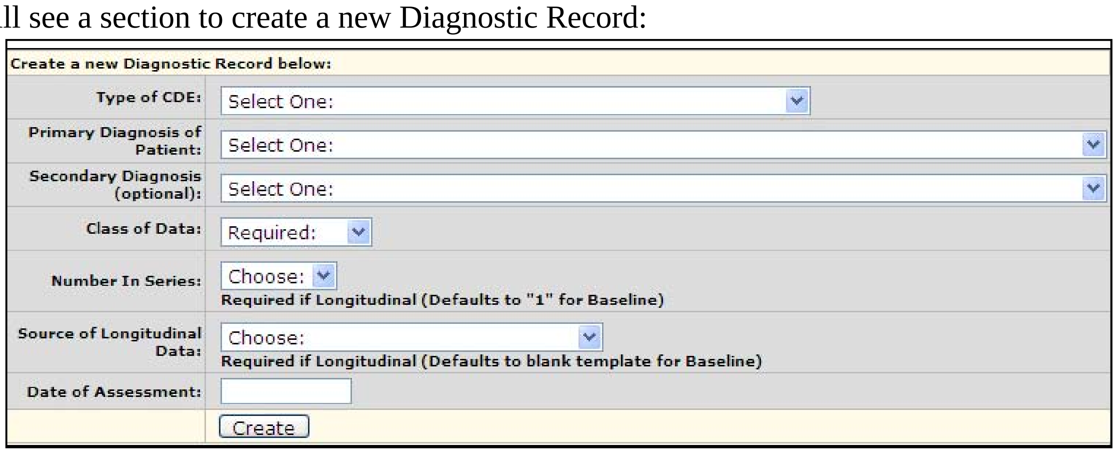
Step 2: Enter Demographic Data

The first three fields concern family data:

- If no family members are to be collected: answer N for Family Collected, and leave the Relation to Proband and Family ID fields blank.
- If other family members are to be collected: answer Y for Family Collected, indicate the relationship to the Proband (the first affected individual in the family), and the Subject IDs or NINDS IDs of the other family members.
- Enter age, gender, race, ethnicity, country of origin, year of birth, affected status, clinical data source, clinician type, first 3 digits of zip code, and age of diagnosis and onset if applicable.

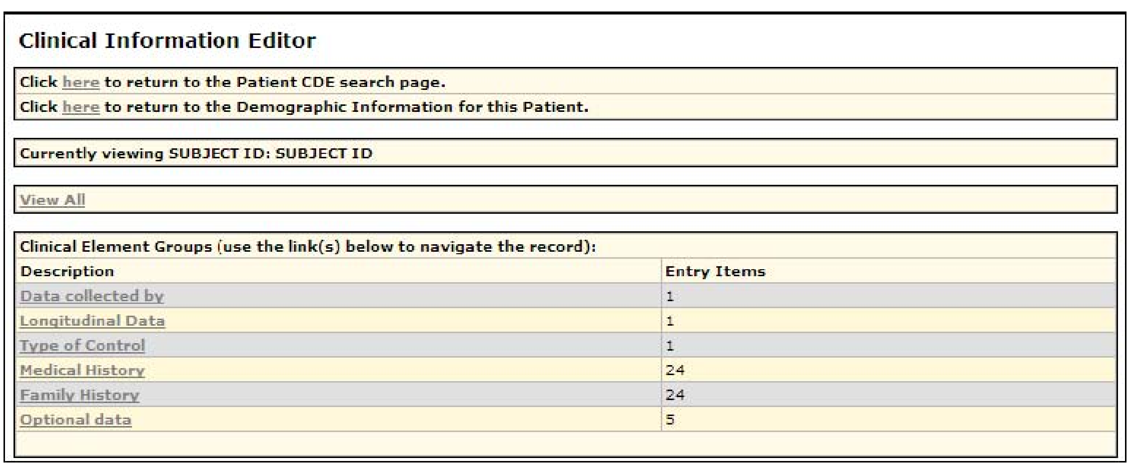
Step 3: Click the **SAVE** button at the bottom of the screen.

Step 4: Enter the Diagnostic Record. Underneath the Demographic fields you just entered, you will see a section to create a new Diagnostic Record:


Create a new Diagnostic Record below:

Type of CDE:	Select One:
Primary Diagnosis of Patient:	Select One:
Secondary Diagnosis (optional):	Select One:
Class of Data:	Required:
Number In Series:	Choose: Required if Longitudinal (Defaults to "1" for Baseline)
Source of Longitudinal Data:	Choose: Required if Longitudinal (Defaults to blank template for Baseline)
Date of Assessment:	
	Create

Step 5: Click the Create button. This will bring you to the next screen:


Clinical Information Editor

Click here to return to the Patient CDE search page.
Click here to return to the Demographic Information for this Patient.

Currently viewing SUBJECT ID: SUBJECT ID

View All

Clinical Element Groups (use the link(s) below to navigate the record):

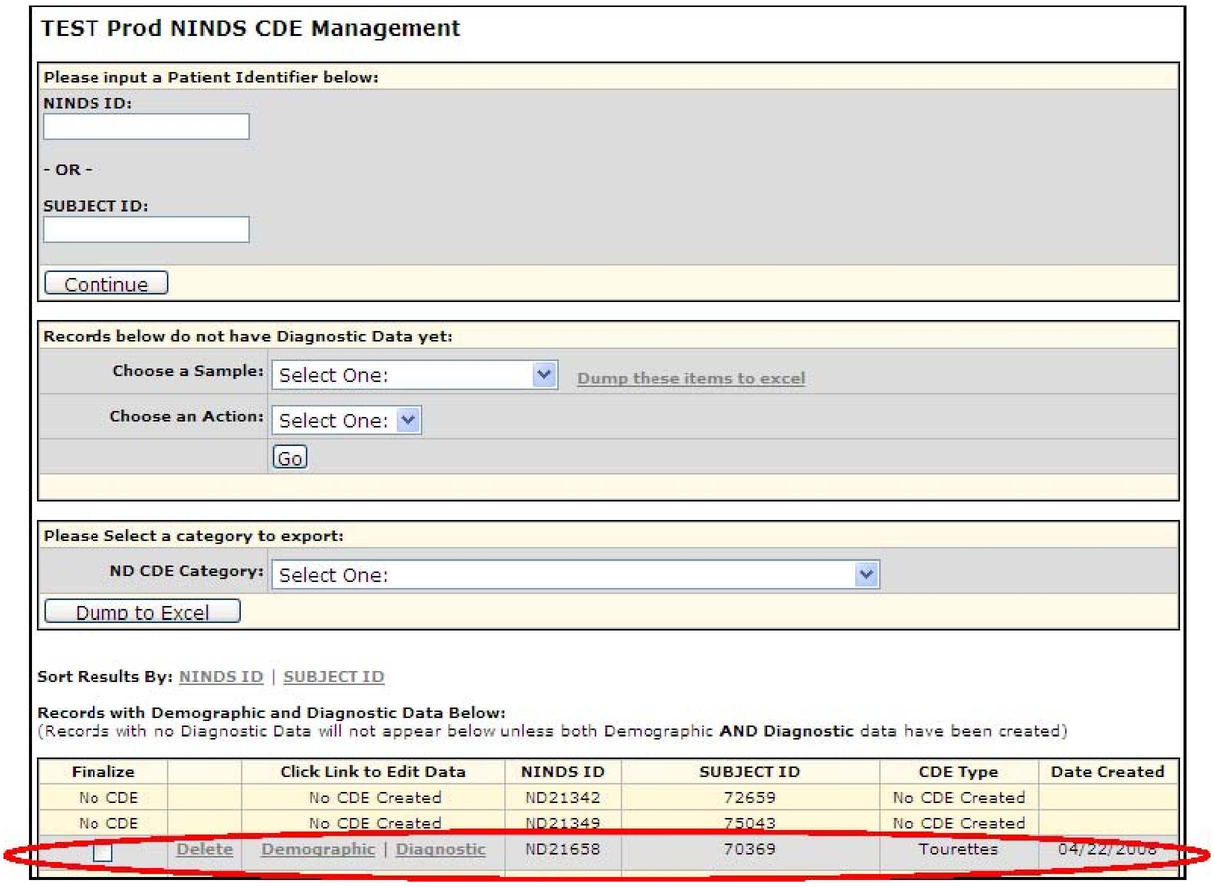
Description	Entry Items
Data collected by	1
Longitudinal Data	1
Type of Control	1
Medical History	24
Family History	24
Optional data	5

- You can select View All to enter all data points at once, or choose one section at a time using the links under Clinical Elements Group.

Important
Be sure to click the save button after entering your data. Once saved, you can navigate away from this CDE and edit it at a later time.

How to Edit an Existing CDE

- Click the CDE Management link.
- CDEs you have previously entered and saved but have yet to finalize (or CDEs that have been returned to you for editing) will be listed on the bottom half of the screen, as circled in red below:



- To edit the saved CDE, click the Demographic or Diagnostic link, make any necessary updates, and save the record.

How to Submit a CDE

- Once you have completed all required data, you'll need to submit the CDE for review.
- Click the CDE Management link.
- Click the box in the Finalize column next to the record you wish to submit.
- Click the Confirm button.

Sort Results By: NINDS ID | SUBJECT ID

Records with Demographic and Diagnostic Data Below:
(Records with no Diagnostic Data will not appear below unless both Demographic **AND Diagnostic** data have been created)

Finalize		Click Link to Edit Data	NINDS ID	SUBJECT ID	CDE Type	Date Created
No CDE		No CDE Created	ND21342	72659	No CDE Created	
No CDE		No CDE Created	ND21349	75043	No CDE Created	
☐	Delete	Demographic | Diagnostic	ND21658	70369	Tourettes	04/22/2008
☑	Delete	Demographic | Diagnostic	NDPENDING	SUBJECT ID	Control	05/07/2009

Confirm | Dump to Excel

- You will then be directed to an auto-review screen. Queue will check that all required data has been entered, and if it has, you will see a PASSED validation at the bottom of the screen. If required data elements are missing, these fields will be flagged in red and you will be directed to edit the missing fields.

CDE Management - Auto-Review Validation

Using the links from this page to edit CDE data will open an editor in a new window. Once you have saved your changes in tha window, please refresh this window in order to revalidate the items listed below. This will ensure all available status update o are available.

Auto-Review for: ND21659 [LOCAL ID:] (View CDE)
Clinical Element Type: Control (Baseline)
Primary Diagnosis: ASYMPTOMATIC OR UNDIAGNOSED AND GENETICALLY RELATED TO AN AFFECTED INDIVIDUAL
Demographic Data Check:

Group Description	Value Description	Validation Result
Demographics	Age	OK
Demographics	Clin_Data_source	OK
Demographics	Clinical_Affected_Status	OK
Demographics	Clinician_Type_id	OK
Demographics	Country	OK
Demographics	Family_Collected	OK
Demographics	Gender	OK
Demographics	Hispanicity	OK
Demographics	Race_id	OK
Demographics	YOB	OK

Diagnostic Data Check (Supplied Data):

Group Description	Element Description	Value Chosen	Validation Result
Medical History	Amyotrophic lateral sclerosis	absent	OK
Medical History	Ataxia	absent	OK
Medical History	Autism	absent	OK
Medical History	Brain aneurysm	absent	OK
Medical History	Cancer	absent	OK
Medical History	Dementia	absent	OK
Medical History	Depression	present	OK
Medical History	Diabetes	absent	OK
Medical History	Obsessive Compulsive	present	OK
Medical History	Tourettes	absent	OK
Type of Control	Type of Control	Related to an affected individual (REQUIRES SPECIAL APPROVAL)	OK
Data collected by	This data was collected by	clinical research assistant/nurse	OK
Longitudinal Data	Is this data Longitudinal (Follow-Up) Data?	no	OK

Diagnostic Data Check (Missing Required Data):

Group Description	Element Description	Value Chosen	Validation Result

All Required Entered!
Validation Status:

PASSED

Status Update: Finalize

Once all CDE's are verified: Continue

- At the bottom of the auto-review screen will be a drop-down menu under Status Update where you will choose a destination for the record. Only options available for a specific record will appear. The possible options are listed below:
    - **Finalize**: When records have all information completed there will be an option to finalize the record. This will submit the record to Coriell for review. Once a record is finalized, you will not longer be able to edit the record unless it is released back to you by a NINDS Project Manager
    - **Take No Action**: In all cases there will be an option to Take No Action. This will make no change to the record's status.
    - **Special Approval**: If a subject is missing required data on their CDE record there will not be an option to finalize the record. If there is a special circumstance in which particular data cannot be obtained the record can be submitted for Special Approval. If you wish to submit a record for Special Approval an email must be sent to the Project Manager and copied to the NINDS Repository PI indicating (1) the subject IDs and (2) the reason that these records should be considered for special approval.

- Once you select a Status Update, click the Continue button at the bottom of the screen. You will be given a confirmation that your CDE has been finalized and submitted for review.

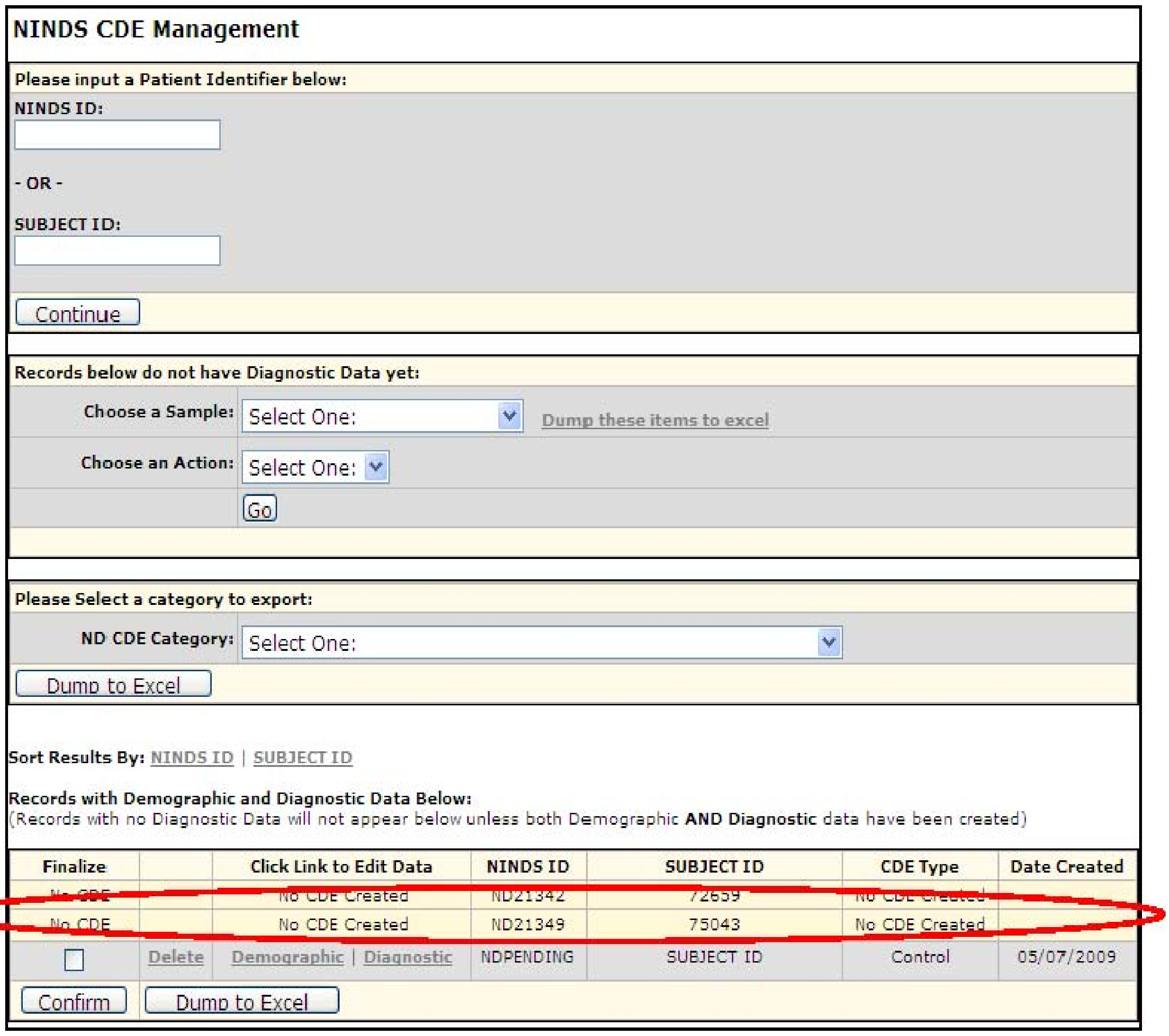
NINDS CDE Management - Auto Review - Summary

The following items have been updated:		
Ref	Cde Type	Action Taken
ND21659	Control	Finalized
Thank you for validating your CDE data - please use the navigation on the left to continue.		

- Note that once a record is finalized, you will no longer be able to make changes electronically. However, if a change is required to a CDE record after it has been finalized, contact a Project Manager for assistance. If you finalize a record, but Coriell staff notices that information is missing, the record will be returned to you for editing and you will be notified via email that additional information is needed for this CDE. You can then update and finalize the record again.

How Can I Determine Which Samples Still need CDEs Created?

When you open your CDE Management page, you will see a list of samples that do not have a CDE created yet. Create and finalize CDEs for these samples according to the instructions on page 10.



Longitudinal Data Entry

Longitudinal data are clinical data collected after initial enrollment/CDE completion. Longitudinal data track a patient's clinical progress over time, and add significant scientific value. When follow-up or additional tests are completed the data can be entered by creating a second CDE, which will be attached to the original baseline CDE and demographic data.

- Identify a subject whose sample and baseline clinical data have previously been submitted to the NINDS Repository. You will need their subject ID or NINDS ID.
- Open the CDE Management page in Queue.
    - Enter the Subject ID or NINDS ID in the appropriate box and click the Continue button.
    - The previously entered demographic data will appear on the next screen. If the subject has expired, enter the date of death in the appropriate box .
    - Scroll down to the Diagnostic Record Management area at the bottom of the page.
    - Select the appropriate Type of CDE (i.e. the same type of CDE as the original record).
    - The Primary Diagnosis field will show the original diagnosis. If the diagnosis has changed since the last visit, select the new diagnosis from the drop-down menu.
    - For Class of CDE, select Longitudinal from the drop-down menu.
    - Next, choose the number of this CDE in the series (Baseline is #1, the first longitudinal record will be #2, etc).
    - Finally, choose the source of the longitudinal data: Baseline, Longitudinal (highest series number), or Blank. This will pre-fill the new CDE with data from either the Baseline or the most recent Longitudinal record entered, or provide you with a new blank template.
    - Click the Create button. A box will appear that asks "Are you sure you want to create more than one diagnostic record?" Select OK.
    - The Clinical Information Editor screen will appear, just as it did when you entered the baseline data.
    - Click on the link to View All.
    - The first question asks "Is this Longitudinal Data?" Select Yes.
    - If working on a CDE pre-filled with data from a previous visit, update any fields that have changed since that visit. If working from a blank template, you must enter all fields.
    - Save the record.
    - Return to the CDE Management page, and Finalize the record as explained on page 15.

Special Note on Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP), Hereditary Hemorrhagic Telegiectasia (HHT), and Cerebral Cavernous Malformations (CCM) Cases

There are some special cases where more than one baseline CDE must be entered per subject.

- PSP Cases: Clinical data for PSP patients must be reported on two CDEs- one PSP CDE and one Parkinsonism CDE.
- MSA Cases: Clinical data for MSA patients must be reported on two CDEs- one MSA CDE, and one Parkinsonism CDE.
- HHT Cases: Clinical data for HHT patients must be reported on two CDEs- one HHT CDE, and one Cerebrovascular Disease CDE.
- CCM Cases: Clinical data for MSA patients must be reported on two CDEs- one CCM CDE, and one Cerebrovascular Disease CDE.

- Create the first CDE as you normally would (the order in which you enter the CDEs is not important).
- To create the second CDE, go to the CDE Management page and enter the same subject ID or NINDS ID in the search box and click Continue. This will bring you to the demographic info page, which should be pre-filled with the data entered from the first CDE.
- Scroll down to the Diagnostic Record Management section and select the Type of CDE and Diagnosis for the second CDE. The class of CDE will still be Baseline.
- Click the Create button. A box will appear asking "Are you sure you wish to create more than one diagnostic record?" Select "Yes", then fill in the clinical info and save the record.

Coriell Sample Review Process

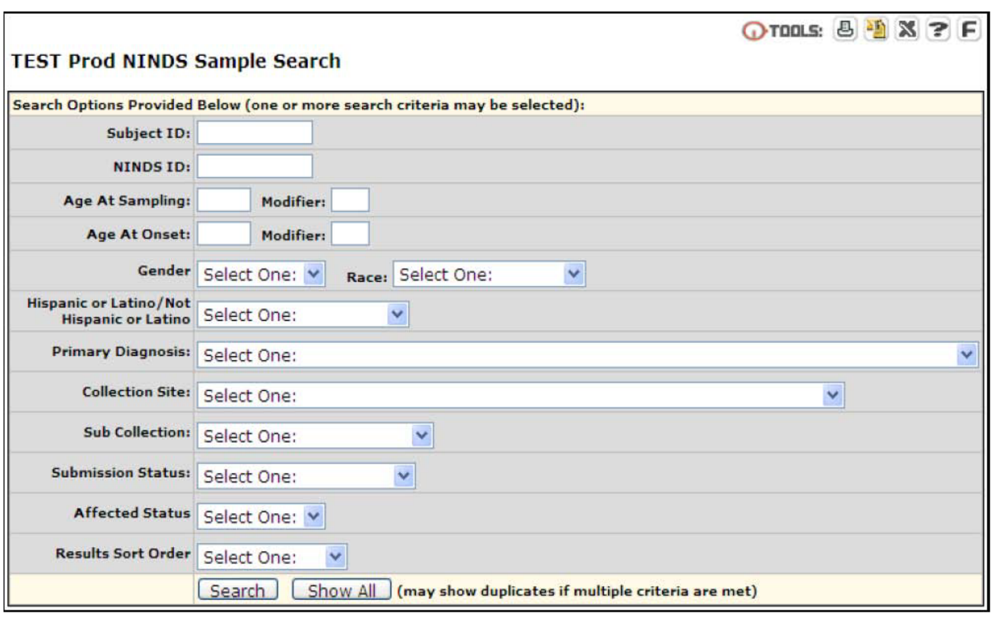
After samples are submitted and data are finalized by a submitter, they are reviewed by the NINDS Repository team at Coriell to ensure that the clinical data elements are complete.

Important
Discount purchase credits and back-in-kind DNA samples will not be returned to the Investigator until all clinical data elements are complete for that sample.

Searching for Samples

How to Use the Search Page

- Click the Search link under the NINDS Project Management menu in Queue.
- Using this page, you may search for samples using multiple criteria, such as: Subject ID, NINDS ID, Age at sampling or onset, Gender, Ethnicity, Diagnosis, Collection Site, Subcollection, Submission Status, Affected Status, or any combination of the above.
- Enter the fields you wish to search under, and click the Search button.
- Search results will provide you with the Collection Site that submitted the sample, the Subject ID, the NINDS ID, the date the sample was received at Coriell, the Submission Status, Demographic Data, and the Diagnosis.
  Search results may be viewed in an Excel spreadsheet by clicking the Build Excel View icon, located in the upper right-hand corner of the screen.



Project Overview Page

This page contains tables to assist you in managing the submissions process. An example of a Project Overview Page is shown below and contains Submitter Information, Submission Information, Shipping History, Sample Review Summary, as well as breakdowns of sample information including gender, age, diagnosis, and race. Links are included in this section that can be used to generate a list of submissions in each category.

NINDS Project Overview

Submitter Information:	
Name:	NINDS
ID:	0000
Institution:	NINDS
Type:	NON-SUPPLEMENTED

Submission Information:	
First:	08/14/2007
Latest:	03/18/2009
Total:	781

Sample Status Summary:	Total
Submitted	781
Banked Cryopreserved Lymphs	614
Banked Cell Lines	7
Banked DNA Samples	603
Subjects in Catalog	0

CDE Submission Status:	See Missing Data	Total
Accept for Clinical Data		617
Project Manager Finalized		0
Reject Submission		2
Special Approval		0
Submitter Finalized		101
Submitter Pending	Go To Autoreview	6
		726
No CDE Record		55

Shipping History:	Total
Back to Submitter	603
Other	0
Remaining @ Reduction	781

Affected Sample Count:	Total
Affected	313
Un-Affected	10
Unknown	53
	376

Repository Assigned Diagnosis of Samples [all submitted samples]:	Total
ASYMPTOMATIC OR UNDIAGNOSED AND GENETICALLY RELATED TO AN AFFECTED INDIVIDUAL	371
TOURETTE SYNDROME	342
DEFAULT DIAGNOSIS	55
UNAFFECTED SPOUSE OF AFFECTED BLOOD RELATIVE	13
Unknown	0
	781

Clinical Data Summary: *Links will download CDE data in excel/.csv format* [submitter finalized CDEs only]	Subjects	Approved	Review Pending	Rejected Approval
Control	43	43	0	0
Tourettes	573	573	0	0
	616	616	0	0

Gender of Samples:	Total
Male	432
Female	295
Unknown	54
	781

Race of Samples:	Total
Caucasian	685
Other	15
Asian	12
More than one race	11
African American	2
Unknown	56
	781

Age Breakdown of Samples:

0 - 20	21 - 40	41 - 60	61 - 80	81 +
239	144	314	27	0

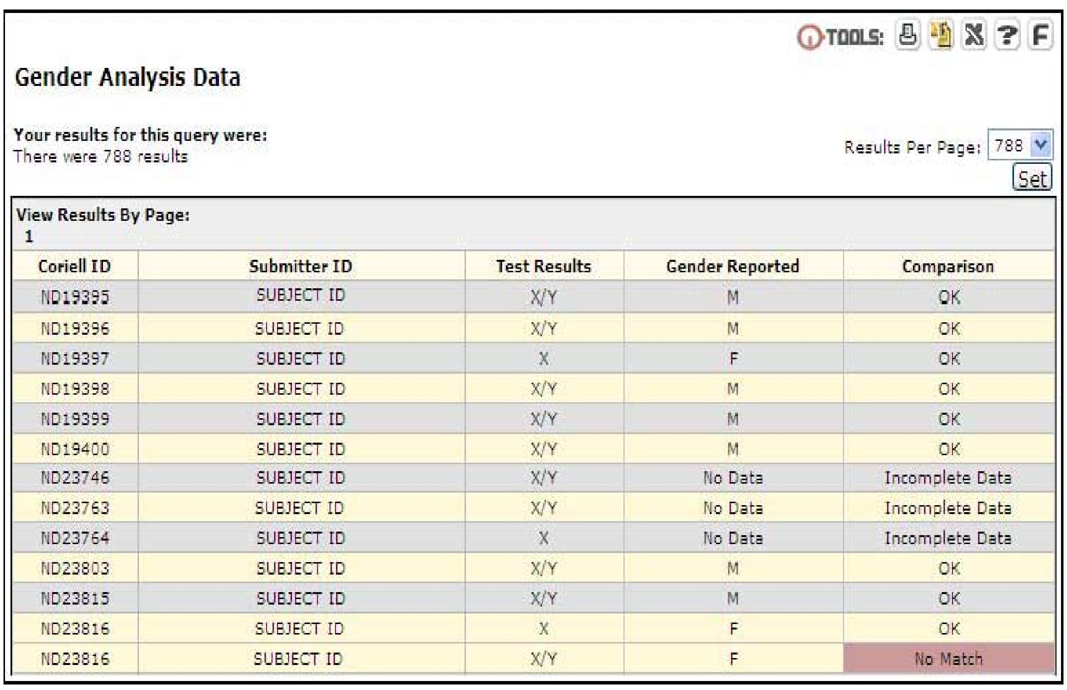
Unknown: 57
Total Counted: 781

Laboratory Data

Laboratory data, including results of gender tests and microsatellite profiles, are available in Queue for all submissions to assist in the quality control of samples in the NINDS Repository.

Gender Data

- For every sample submitted to the NINDS Repository, a gender test is performed to confirm the reported gender.
- Using this report, submitters can view the results of these gender tests.
- Click the Gender Data link under the NINDS Project Management main menu. A list of Subject IDs and NINDS IDs are displayed along with the reported gender and the results of the gender test.
- Samples where the reported gender conflicts with the results of the gender test will be noted.
- Samples where no gender data has been reported by the submitter will also be noted.
- Gender data can be viewed and saved in Excel format by clicking the Excel icon in the upper right-hand corner of the screen.


TOOLS:

Gender Analysis Data

Your results for this query were:
There were 788 results

Results Per Page: 788
Set

View Results By Page:
1

Coriell ID	Submitter ID	Test Results	Gender Reported	Comparison
ND19395	SUBJECT ID	X/Y	M	OK
ND19396	SUBJECT ID	X/Y	M	OK
ND19397	SUBJECT ID	X	F	OK
ND19398	SUBJECT ID	X/Y	M	OK
ND19399	SUBJECT ID	X/Y	M	OK
ND19400	SUBJECT ID	X/Y	M	OK
ND23746	SUBJECT ID	X/Y	No Data	Incomplete Data
ND23763	SUBJECT ID	X/Y	No Data	Incomplete Data
ND23764	SUBJECT ID	X	No Data	Incomplete Data
ND23803	SUBJECT ID	X/Y	M	OK
ND23815	SUBJECT ID	X/Y	M	OK
ND23816	SUBJECT ID	X	F	OK
ND23816	SUBJECT ID	X/Y	F	No Match

Microsatellite Data

- For every sample submitted to the NINDS Repository, a microsatellite profile is generated. Results can be viewed by clicking the Microsatellite Data link under the NINDS Project Management main menu. A list of Subject IDs and NINDS IDs are displayed along with the gender, relationship to Proband, NINDS family ID number, and microsatellite profile.
- Microsatellite data can be viewed in Excel format by clicking the Excel icon in the upper right-hand corner of the screen

TOOLS:

Microsatellite Search Response

Your results for this query were:
There were 1437 results

Results Per Page: 1437 Set

View Results By Page:
1

Coriell ID	Submitter ID	Gender	Relationship	Run Date	THO-1	D5S592	D10S526	VWA31	D22S417	FES/FPS	Fam #
ND19395	SUBJECT ID	M	proband	8/23/2007	171 171	178 182	194 246	149 149	185 189	228 228	NINDS2175
ND19395	SUBJECT ID	M	proband	9/5/2007	171 171	178 182	194 246	149 149	185 189	228 228	NINDS2175
ND19396	SUBJECT ID	M	father	8/23/2007	171 175	178 198	194 206	149 161	173 185	220 228	NINDS2175
ND19396	SUBJECT ID	M	father	8/28/2007	171 175	178 198	194 206	149 161	173 185	220 228	NINDS2175
ND19397	SUBJECT ID	F	mother	8/23/2007	163 171	182 182	202 246	149 153	185 189	220 228	NINDS2175
ND19397	SUBJECT ID	F	mother	8/28/2007	163 171	182 182	202 246	149 153	185 189	220 228	NINDS2175

Shipping History

This page allows you to view all orders of back-in-kind DNA that have been shipped to you.

Click the Shipping History link under the NINDS Project Management main menu.

- Click the Shipping History link under the NINDS Project Management main menu.
- A report will be displayed providing the order ID, order date, ship date, the type of product and quantity shipped, and the recipient info.
- Further details of each order, including the NINDS IDs and Subject IDs of the samples shipped, can be seen by clicking the View link next to each order listed.
- Results can be viewed in Excel format by clicking the Excel icon in the upper right hand corner of the screen.

TOOLS:

TEST Prod Shipping History Search Response

Your selection(s)for this query were:

Ref #	Start Date	End Date	Order Id	Last Name
Search All				

Dump all results with full details to Excel: Go!
****WARNING** This may require a long loading time!**

Your results for this query were:
There were 11 results

Results Per Page: 12 Set

View Results By Page:
1

Order Id	Order Date	Ship Date	Qty	Product Type	Order Type	RI Type	Last Name	Institution Name	Report
69359	03/11/2009	03/11/2009	5	DNA	Back to submitter	No Data	Name	Institution	View

Additional Functions & Tools

Feedback

This feature is devoted to facilitating communication between Coriell's Information Systems Team and the Queue system end users in order to improve the Queue system to better meet the needs of the end users.

Please note that this feedback is sent directly to the Information Systems Team and is used for comments or suggestions from the technical perspective. The feedback is not for other NINDS Repository comments related to samples or data. These comments should be emailed to a Project Manager.

- If you have a technical comment/suggestion when on a particular screen, click on the "F" icon located in the upper right-hand corner of that screen. A box will appear in which you type a comment. The feedback will then be linked to the particular screen.
- To view a summary of the feedback you have submitted and its current status, go to the Resources link in the upper left-hand corner of the page, then select Feedback from the menu that appears. Then click the Feedback List link.
- A report of all feedback you have submitted and the resolution status will be displayed.

Q-Help

This section of the site is devoted to helping users get the most out of Queue. From frequently asked questions to fixes to common problems, this section of the site will cover it all. Included in this section are functional breakdowns to facilitate ease of use for any level of user.

Q-Map

This section lists the current features you can access in Queue.

Tools

This section of the site is devoted to tools that will assist the user in navigating the system as well as offer other informational devices such as virtual tours.

Functional Tools

This section will be located at the top right corner (TOOLS) of the screen below the login information. The tools will only appear when they are available to the screen currently being accessed.

- The Q Memory feature is used for book marking sections. When using a Queue page that you regularly access that does not appear on the main menu, you can check the box at the top right of the page. This will introduce a link to the page under Q Memory Links, which will appear to the left of your screen. Up to 10 links can be displayed on the list.
- Selecting the printer icon will display the page so it is printer friendly.

- Selecting the mail icon allows the screen to be emailed.
- Selecting the excel icon will display the information on the page in an Excel Spreadsheet.
- Selecting the question mark (?) icon will access the help function.

Contact Information

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403 Haddon Avenue
Camden, NJ 08103
Fax: 856-966-5067

Web Links

NINDS Repository Catalog: http://ccr.coriell.org/ninds/

Queue website: https://queue.coriell.org/q/

Coriell Website: http://www.coriell.org/

NINDS Website: http://www.ninds.nih.gov/