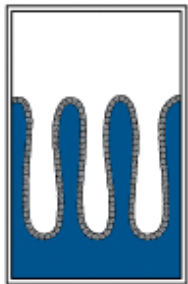


International Intestinal Transplant Registry (ITR)

A primer presentation for data entry

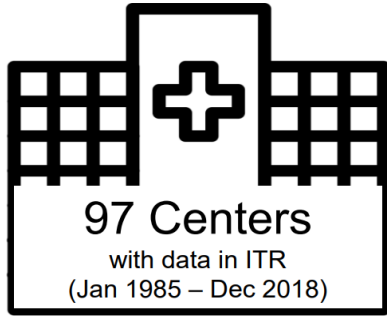
support@intestinalregistry.org



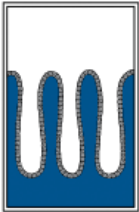
Intestinal Rehabilitation & Transplant
ASSOCIATION



a section
The Transplantation
Society



The
Transplantation
Society



Intestinal Rehabilitation & Transplant
ASSOCIATION



Accessing the Registry

- <https://intestinalregistry.org>
- Sign in using your username and password
- Need to set-up an account for data entry? Forgot password or username?
 - Please contact our support support@intestinalregistry.org

intestinalregistry.org



Intestinal Rehabilitation & Transplant
ASSOCIATION



Welcome to the home of the Intestinal Failure Registry and the Intestine Transplantation Registry!

- To access the Registries (Redcap) [click here](#)
- To access the IRTA website [click here](#)



Log In

Please log in with your user name and password. If you are having trouble logging in, please contact [Terasaki ITRA Registry Admin](#).

Username:

Password:

Log In

[Forgot your password?](#)

Contact Us - Inquiries

- About a project
- Add a user or center to a Registry
- Ask a data entry question
- Submit a data request
- Request a standard analysis file
- Sponsor the registry
- Contact us with general questions

Submitted inquiries are collected and sent to Scientific Committee and Technology Support staff.

After you log in...

Click on ITR Project link:

REDCap™ Home My Projects + New Project Help & FAQ M

Listed below are the REDCap projects to which you currently have access. Click the project link to review which users still have access to the project's [Access Dashboard](#).

Project Title
International Intestinal Transplant Registry (IITR)

REDCap 8.11.7 - © 2019 Vanderbilt University

My Projects Organize

Data collection forms for the IITR: Includes baseline (pre-/peri-transplant) and annual post-transplant data collection.

Project Home page:

REDCap™

Logged in as **jbrennan.test** | Log out

My Projects Project Home REDCap Messenger

Project status: **Production**

International Intestinal Transplant Registry (IITR)

Project Home

Quick Tasks

Codebook

The Codebook is a human-readable, read-only version of the project's Data Dictionary and serves as a quick reference for viewing field attributes.

Data Collection

- Record Status Dashboard
- Add / Edit Records

Applications

- Field Comment Log

Reports Search

- Center Duplicates
- trial
- Indication UK patients
- UCLA HLA
- ucla
- transplant follow up form data - fix
- number of patients
- number of patients (peds)
- clinicalevent
- EBV/CMV report
- Living donor intestinal transplant
- HLA_typing_2017&after
- hosp

Help & Information

- Help & FAQ
- Video Tutorials
- Suggest a New Feature

Contact REDCap administrator

Download codebook

Navigation menu

Status Event

Baseline Intake

Clinical Event

Annual Follow-up

Transplant ID	Status Event		Baseline						Clinical Event		Year1			Year2			Year3			Year4		
	Graft Removal or Death	Last Date of Follow-up with Full Function	Baseline Transplant Intake Form	CMV/EBV Serostatus Form	Recipient HLA Typing Form	Donor HLA Typing Form	HLA Antibody Testing Form	Detailed Biopsy (Pathology) Form	HLA Antibody Testing Form	Detailed Biopsy (Pathology) Form	Transplant Follow Up Form	HLA Antibody Testing Form	Detailed Biopsy (Pathology) Form	Transplant Follow Up Form	HLA Antibody Testing Form	Detailed Biopsy (Pathology) Form	Transplant Follow Up Form	HLA Antibody Testing Form	Detailed Biopsy (Pathology) Form	Transplant Follow Up Form	HLA Antibody Testing Form	Detailed Biopsy (Pathology) Form
-1	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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-7	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
-8	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>

1 transplant = 1 record

Time Points



1. Patient ID
2. Baseline intake
3. CMV/EBV Serostatus
4. Recipient HLA typing
5. Donor HLA typing
6. Biopsy Pathology

1. Transplant Follow-up
2. HLA antibody testing
3. Biopsy Pathology

1. HLA antibody testing
2. Biopsy Pathology

1. Graft removal or death
2. Last date of follow-up with full function

Data Entry Forms

1 transplant = 1 record

Baseline Forms

Baseline Transplant Intake Form

International Intestinal Transplant Registry (IITR)

Actions: [Download PDF of instrument\(s\)](#) [Share instrument in the Library](#) [VIDEO: Basic data entry](#)

Baseline Transplant Intake Form

Assign record to a Data Access Group? -- select a group --

Adding new Transplant ID 1000017

Event Name: **Baseline**

Transplant ID *Assigned transplant id*

Intestinal failure registry ID (please enter the patient ID if the patient was in the intestinal failure registry)

Recipient UNOS ID

Is this a re-transplant? Yes No reset

Gender Male Female reset

Date of transplant: Today reset

Age at transplant (years)

Height at Transplant (cms)

Weight at Transplant (kg) kilograms (kg)

Total Wait time (months):

Diagnosis

Short Gut (Massive Intestinal Resection) Volvulus Gastroschisis Trauma Necrotizing Enterocolitis Ischemia Crohn's Disease Intestinal Atresia Other

Round radio button: you can only pick 1 response.

Pay attention to the formats for dates.

Square checkboxes: you can pick more than 1 response options (check all that apply).

CMV/EBV Serostatus Form

For all forms, “field notes” can provide clarification on different fields.

Field notes are also available in the codebook.

CMV/EBV Serostatus Form

Assign record to a Data Access Group? -- select a group --

Adding new Transplant ID 1000017

Event Name: **Baseline**

Transplant ID 1000017

Donor Serostatus

CMV serostatus of DONOR

Negative
 Positive
 Not available

Was the donor positive for CMV?

EBV serostatus of DONOR

Negative
 Positive
 Not available

Recipient Serostatus

CMV serostatus of RECIPIENT

Negative
 Positive
 Not available

Was the recipient positive for CMV prior to transplant?

EBV serostatus of RECIPIENT

Negative
 Positive
 Not available

Was the recipient positive for EBV (EBV IgG positive) prior to transplant?

CMV monitoring and prophylaxis

CMV Preventative Strategy

Preemptive (monitoring without prophylaxis)
 Universal prophylaxis
 Universal prophylaxis followed by preemptive
 None

Recipient HLA Typing Form

Fields with red text are required to be entered in order for the form to be “complete.”

Again, “field notes” in blue text beneath the field can provide clarification on different fields.

Recipient HLA Typing Form

Assign record to a Data Access Group?

Adding new Transplant ID **1000017**

Event Name: **Baseline**

Transplant ID: 1000017

Date of Completion: Today M-D-Y

Other Centre Specific Identifying information (Optional):

HLA Typing - Recipient (note that you need 2 fields for each locus)

Serologic or Molecular Typing? Serologic typing data (ex. A2, DR4, DQ5) Molecular typing data (ex. A*0201, DRB1*0402, DQB1*0502)
(choose one - molecular preferred)

A-locus #1
*** must provide value**

A-locus #2
*** must provide value**

B-locus #1
*** must provide value**

B-locus #2
*** must provide value**

Is Bw locus information available? Yes No
*** must provide value**

C-locus #1 (aka Cw)

C-locus #2 (aka Cw)

DRB1-locus #1 (aka DR)
*** must provide value**

DRB1-locus #2 (aka DR)
*** must provide value**

DRB345 #1

Donor HLA Typing Form

Again, fields with red text are required to be entered in order for the form to be “complete.”

Donor HLA Typing Form

Assign record to a Data Access Group?

Adding new Transplant ID **1000017**

Event Name: **Baseline**

Transplant ID: 1000017

Date of Completion: Today M-D-Y

HLA Typing - Donor

Serologic or Molecular Typing? Serologic typing data (ex. A2, DR4, DQ5) Molecular typing data (ex. A*0201, DRB1*0402, DQB1*0502) reset
(choose one - molecular preferred)

A-locus #1
* must provide value
example: please enter A*0201 as 0201 (molecular) or 2 (serologic)

A-locus #2
* must provide value
example: please enter A*0201 as 0201 (molecular) or 2 (serologic)

B-locus #1
* must provide value
example: please enter B*4501 as 4501 (molecular) or 45 (serologic)

B-locus #2
* must provide value
example: please enter B*4501 as 4501 (molecular) or 45 (serologic)

Is Bw locus information available? Yes No reset
* must provide value

C-locus #1 (aka Cw)
example: please enter C*0203 as 0203 (molecular) or 2 (serologic)

C-locus #2 (aka Cw)
example: please enter C*0203 as 0203 (molecular) or 2 (serologic)

DRB1-locus #1 (aka DR)
* must provide value
example: please enter DRB1*0401 as 0401 (molecular) or 4 (serologic)

DRB1-locus #2 (aka DR)
* must provide value
example: please enter DRB1*0401 as 0401 (molecular) or 4 (serologic)

DRB345 #1
list as DR51, DR52, or DR53

DRB345 #2
list as DR51, DR52, or DR53

HLA Antibody Testing Form

HLA Antibody Testing Form

Assign record to a Data Access Group? -- select a group --

Adding new Transplant ID 1000017

Event Name: **Baseline**

Transplant ID 1000017

Date of Completion: Today M-D-Y

Post Transplant

Please upload your HLA Screening (DSA Screening) report on this patient. [Upload document](#)

Please black out the patient identifiers and write the registry ID on the form before uploading

DSA positive: Yes No Unknown

Notes or Comments:

Form Status

Complete?

Please upload your HLA Screening (DSA Screening) report on this patient. [Upload document](#)

Please black out the patient identifiers and write the registry ID on the form before uploading

If DSA Positive = "Yes," additional questions are revealed.

If Yes - then Date First Detected: Today M-D-Y

How many Class I DSA (HLA-A, HLA-B or HLA-C) DSA were positive?

How many Class II DSA (HLA-DR, HLA-DQ or HLA-DP) DSA were positive?

Is the patient being treated for DSA or a rejection associated with the DSA? Yes No

Detailed Biopsy (Pathology) Form

Detailed Biopsy (Pathology) Form

Assign record to a Data Access Group? -- select a group --

Adding new Transplant ID 1000017

Event Name: **Baseline**

Transplant ID 1000017

Was a biopsy performed? *If Biopsy = "Yes," additional questions are revealed.* Yes No reset

Select type of biopsy For Cause (suspected rejection/dysfunction) Routine Protocol (standard of care) reset

Date of biopsy Today M-D-Y

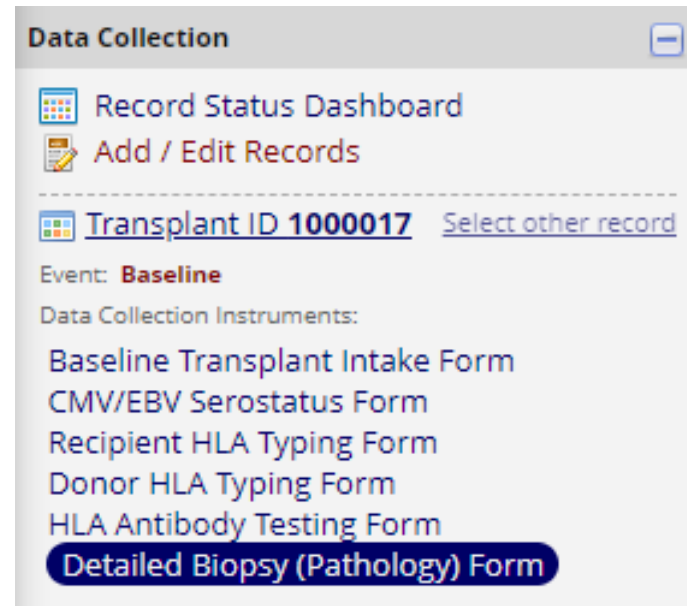
Remember: Square checkboxes mean that you can pick more than 1 response option (check all that apply).

Result
(Check all that apply)

- Normal
- Indeterminate
- Acute T-cell mediated rejection, MILD
- Acute T-cell mediated rejection, MODERATE
- Acute T-cell mediated rejection, SEVERE
- Antibody mediated rejection
- Antibody mediated rejection with c4d positivity
- Chronic antibody mediated rejection
- Chronic T-cell mediated rejection
- Recurrent disease
- Infectious changes
- Ischemic changes
- Bacterial overgrowth
- Pseudomembranous colitis
- Vascular thrombosis
- Preservation injury
- Regenerative changes
- Other

	No	Yes	Not available
Crypt epithelial injury reset	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Crypt epithelial inflammation reset	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Quickly navigate between forms:



The screenshot shows a window titled "Data Collection" with a close button in the top right corner. The window contains the following elements:

- Record Status Dashboard (with a grid icon)
- Add / Edit Records (with a pencil icon)
- A dashed horizontal line separator.
- Transplant ID **1000017** (with a grid icon) and a link [Select other record](#).
- Event: **Baseline**
- Data Collection Instruments:
- Baseline Transplant Intake Form
- CMV/EBV Serostatus Form
- Recipient HLA Typing Form
- Donor HLA Typing Form
- HLA Antibody Testing Form
- Detailed Biopsy (Pathology) Form** (highlighted with a blue background)

Clinical Event

HLA Antibody Testing Form

HLA Antibody Testing Form

Assign record to a Data Access Group?

Adding new Transplant ID 1000017

Event Name: **Clinical Event** ← Clinical Event time point.

Transplant ID 1000017

Date of Completion: M-D-Y

Post Transplant

Please upload your HLA Screening (DSA Screening) report on this patient. [Upload document](#)
Please black out the patient identifiers and write the registry ID on the form before uploading

DSA positive: **If DSA Positive = "Yes," additional questions are revealed below:**
 Yes
 No
 Unknown
[reset](#)

If Yes - then Date First Detected: M-D-Y

How many Class I DSA (HLA-A, HLA-B or HLA-C) DSA were positive?
* must provide value

How many Class II DSA (HLA-DR, HLA-DQ or HLA-DP) DSA were positive?
* must provide value

Is the patient being treated for DSA or a rejection associated with the DSA?
 Yes
 No
[reset](#)

Notes or Comments:
[Expand](#)

Form Status

Detailed Biopsy (Pathology) Form

Detailed Biopsy (Pathology) Form

Assign record to a Data Access Group? -- select a group --

Adding new Transplant ID 1000017

Event Name: **Clinical Event**

Transplant ID 1000017

Was a biopsy performed? **If Biopsy = "Yes," additional questions are revealed below.** Yes No [reset](#)

Select type of biopsy For Cause (suspected rejection/dysfunction) Routine Protocol (standard of care) [reset](#)

Date of biopsy M-D-Y

Result

(Check all that apply)

- Normal
- Indeterminate
- Acute T-cell mediated rejection, MILD
- Acute T-cell mediated rejection, MODERATE
- Acute T-cell mediated rejection, SEVERE
- Antibody mediated rejection
- Antibody mediated rejection with c4d positivity
- Chronic antibody mediated rejection
- Chronic T-cell mediated rejection
- Recurrent disease
- Infectious changes
- Ischemic changes
- Bacterial overgrowth
- Pseudomembranous colitis
- Vascular thrombosis
- Preservation injury
- Regenerative changes
- Other

	No	Yes	Not available
Crypt epithelial injury	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Annual Forms

Year 1, Year 2 .. Year 30

Transplant Follow Up Form

Transplant Follow Up Form

Assign record to a Data Access Group?

-- select a group --

Adding new Transplant ID 1000017

Event Name: Year1

Transplant ID

1000017

Date of Follow-up



31

Today

M-D-Y

Patient Status

Is the patient Lost to follow-up or has the care been transferred to another center?



- Yes
 No

reset

Current Graft Function



- Full Function (no PN or IV Fluids)
 Partial Function (IV Fluids Required but no Parenteral Nutrition)
 Partial/No Function (Requires some or total Parenteral Nutrition)
 Unknown

reset

Modified Karnofsky Performance Score



- 90%-100%: Well or minor symptoms. Resumed normal activities.
 61%-89%: Able to care for self as appropriate for age, but unable to resume normal activities
 31%-60%: Requires significant assistance. Home bound.
 1%-30%: Hospital bound.
 Unknown

reset

Dialysis / Renal Replacement Therapy

Since the last follow-up has the patient on renal replacement therapy, dialysis, or received a kidney transplant ?



- Yes
 No

reset

What is the current immunosuppression?

What is the immunosuppression regimen as of the last follow-up appointment?



- Early failure before maintenance immunosuppressive therapy was started
 No maintenance immunosuppression
 The patient was on immunosuppression

HLA Antibody Testing Form

HLA Antibody Testing Form

Assign record to a Data Access Group? -- select a group --

Adding new Transplant ID 1000017

Event Name **Year1**



Follow-up Year

Transplant ID

1000017

Date of Completion:

Today M-D-Y

Post Transplant

Please upload your HLA Screening (DSA Screening) report on this patient.

[Upload document](#)

Please black out the patient identifiers and write the registry ID on the form before uploading

DSA positive:

If DSA Positive = "Yes," additional questions are revealed below:

Yes
 No
 Unknown

reset

If Yes - then Date First Detected:

Today M-D-Y

How many Class I DSA (HLA-A, HLA-B or HLA-C) DSA were positive?

* must provide value

How many Class II DSA (HLA-DR, HLA-DQ or HLA-DP) DSA were positive?

* must provide value

Is the patient being treated for DSA or a rejection associated with the DSA?

Yes
 No

reset

Notes or Comments:

Expand

Form Status

Detailed Biopsy (Pathology) Form

Detailed Biopsy (Pathology) Form

Assign record to a Data Access Group? -- select a group --

Adding new Transplant ID 1000017

Event Name: **Year1**

Transplant ID 1000017

Was a biopsy performed? **If Biopsy = "Yes," additional questions are revealed below.**

Yes
 No

Select type of biopsy

For Cause (suspected rejection/dysfunction)
 Routine Protocol (standard of care)

Date of biopsy

Today M-D-Y

Result

(Check all that apply)

- Normal
- Indeterminate
- Acute T-cell mediated rejection, MILD
- Acute T-cell mediated rejection, MODERATE
- Acute T-cell mediated rejection, SEVERE
- Antibody mediated rejection
- Antibody mediated rejection with c4d positivity
- Chronic antibody mediated rejection
- Chronic T-cell mediated rejection
- Recurrent disease
- Infectious changes
- Ischemic changes
- Bacterial overgrowth
- Pseudomembranous colitis
- Vascular thrombosis
- Preservation injury
- Regenerative changes
- Other

Status Event

Graft Removal or Death

Graft Removal or Death

Assign record to a Data Access Group? -- select a group --

Adding new Transplant ID 1000017

Event Name: Status Event

Transplant ID 1000017

Patient Status

If graft failure selected, additional questions are revealed below:

- Death
- Graft failure but still alive

Final Transplant Status

Graft Status

Date of Graft Failure/Removal

Today M-D-Y

Cause for Graft Failure/Removal

- Rejection
- PTLD
- Infection (non-PTLD)
- Surgical (Thrombosis or volvulus, etc)
- Poor Graft Function
- Other
- Death

Other Reason for or Comments on Graft Removal:

Additional Comments (next ITR transplant ID, additional graft loss info, etc)

Form Status

Complete?

Incomplete

If patient died, additional questions are revealed below:

Final Transplant Status

- Death
- Graft failure but still alive

Date of Death:

Today M-D-Y

Cause of Death

No Yes


Sepsis/Infection

Lymphoma

Last Date of Follow-up with Full Function

Last Date of Follow-up with Full Function

Assign record to a Data Access Group?


 Adding new Transplant ID 1000017

Event Name: **Status Event**

Transplant ID 1000017

Last Date of Full Function

Last date of full function (date when patient dies, is started on PN, has graft removed, or is lost to follow-up)

 Today M-D-Y

Comments

How do I...?

Add a new transplant?

REDCap™

Logged in as **jbrennan** | Log out

- My Projects
- Project Home
- Project Setup

Project status: **Production**

Data Collection

- Record Status Dashboard
- Add / Edit Records**

Applications

- Data Exports, Reports, and Stats
- Data Import Tool
- Data Comparison Tool
- Logging
- Field Comment Log
- User Rights and DAGs
- API and API Playground

Reports [Edit reports](#)

International Intestinal Transplant Registry (IITR)

Add / Edit Records

You may view an existing record/response by selecting it from the drop-down lists below. To create a new record/response, click the button below.

Total records: **3,530**

Choose an existing Transplant ID

Data Search

Choose a field to search
(excludes multiple choice fields)

Search query
Begin typing to search the project data, then click an item in the list to navigate to that record.

1. →

2. ←

Start with the Baseline forms...

International Intestinal Transplant Registry (IITR)

Record Home Page

Record "100017" is a new Transplant ID. To create the record and begin entering data for it, click any gray status icon below.

The grid below displays the form-by-form progress of data entered for the currently selected record. You may click on the colored status icons to access that form/event. If you wish, you may modify the events below by navigating to the [Define My Events](#) page.


Legend for status icons:

- Incomplete ? Incomplete (no data saved)
- Unverified ● ● ● Many statuses (all same)
- Complete ● Many statuses (mixed)

NEW Transplant ID 100017

Data Collection Instrument	Status Event	Baseline	Clinical Event	Year1	Year2	Year3	Year4	Year5	Year6	Year7
Baseline Transplant Intake Form		<input type="radio"/>								
CMV/EBV Serostatus Form		<input type="radio"/>								
Transplant Follow Up Form									<input type="radio"/>	<input type="radio"/>
Recipient HLA Typing Form		<input type="radio"/>								
Donor HLA Typing Form		<input type="radio"/>								
HLA Antibody Testing Form		<input type="radio"/>							<input type="radio"/>	<input type="radio"/>
Detailed Biopsy (Pathology) Form		<input type="radio"/>							<input type="radio"/>	<input type="radio"/>
Graft Removal or Death	<input type="radio"/>									
Last Date of Follow-up with Full Function	<input type="radio"/>									

1. Patient ID (*automatic*)
2. Baseline Intake form
3. CMV/EBV Serostatus
4. Recipient HLA typing
5. Donor HLA typing
6. Biopsy Pathology

To fill in each form, select the gray circle  next to each form title.

Update an existing transplant?

REDCap™

Logged in as **jbrennan** | Log out

- My Projects
- Project Home
- Project Setup
- Project status: **Production**

Data Collection

- Record Status Dashboard
- Add / Edit Records**

Applications

- Data Exports, Reports, and Stats
- Data Import Tool
- Data Comparison Tool
- Logging
- Field Comment Log
- User Rights and DAGs
- API and API Playground

Reports | [Edit reports](#)

International Intestinal Transplant Registry (IITR)

Add / Edit Records

You may view an existing record/response by selecting it from the drop-down lists below. To create a new record/response, click the button below.

Total records: **3,530**

Choose an existing Transplant ID | -- select record -- | Add new record

Data Search

Choose a field to search
(excludes multiple choice fields) | All fields

Search query
Begin typing to search the project data, then click an item in the list to navigate to that record.

Example of an existing transplant record for Transplant ID 99-99:

Record Home Page

The grid below displays the form-by-form progress of data entered for the currently selected record. You may click on the colored status icons to access that form/event. If you wish, you may modify the events below by navigating to the [Define My Events](#) page.

Choose action for record ▾

Transplant ID 99-99
Center Name

Table not displaying properly ?

Legend for status icons:

- Incomplete ?
- Unverified ?
- Complete ?
- Incomplete (no data saved) ?
- ● ● Many statuses (all same)
- Many statuses (mixed)

Data Collection Instrument	Status Event	Baseline	Clinical Event	Year1	Year2	Year3
Baseline Transplant Intake Form		●				
CMV/EBV Serostatus Form		●				
Transplant Follow Up Form				●	●	●
Recipient HLA Typing Form		●				
Donor HLA Typing Form		●				
HLA Antibody Testing Form		●	●	●	●	●
Detailed Biopsy (Pathology) Form		●	●	●	●	●
Graft Removal or Death	●					
Last Date of Follow-up with Full Function	●					
Delete all data on event:		✘		✘	✘	✘

Form Status:

Indicates if the form was marked as “Incomplete,” “Unverified,” or “Complete.”

Gray circles indicate that the form is completely empty.

This transplant has:

- All annual follow-up forms completed
- 4 out of 6 baseline forms completed
- 1 baseline form entered but unverified.
- 1 baseline form missing.

What do we do with this data?

Annual Registry Report



Intestinal Rehabilitation and Transplant Association
A section of the Transplantation Society

International Intestinal Transplant Registry

2019 Report

Intestinal Transplant Registry Report © 2018

Overall Registry Dashboard

Monthly update
for IRTA Scientific
Committee



ITR Dashboard - September 2019

Introduction

Overview

Missing Fields - 2019

Missing Fields - All ITR

Missing Fields - US

Missing Fields - Outside US

Go to the Registry

International Intestinal Transplant Registry (ITR)

ITR data current as of: **September 18, 2019**

How to Use This Dashboard:

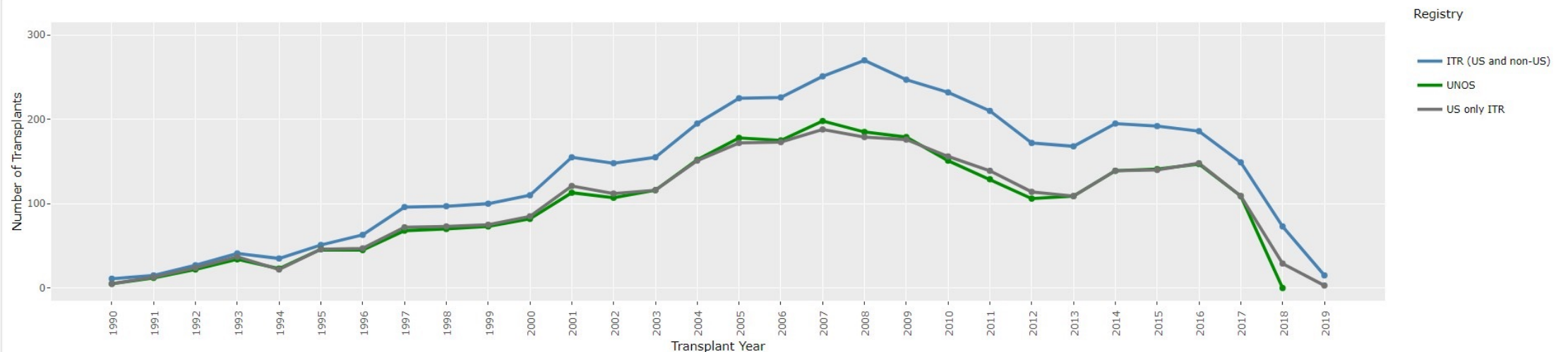
This report displays tables, figures, and data quality information for the entire Intestinal Transplant Registry.

Please click on the different titles in the header to access data about:

1. Introduction
2. Overview
3. Missing Fields - 2019
4. Missing Fields - All ITR
5. Missing Fields - U.S.
6. Missing Fields - Outside U.S.

If you have any questions about this report or the registry, please contact: redcap@terasaki.org

Number of Transplants in ITR by Year



Single Center Report Dashboard

ITR Center Dashboard - October 2019

Introduction

Center Overview

Missing Fields - 2019

Missing Fields - Recent Years

Action Items

Patient List

Go to the Registry

International Intestinal Transplant Registry (ITR) Center:

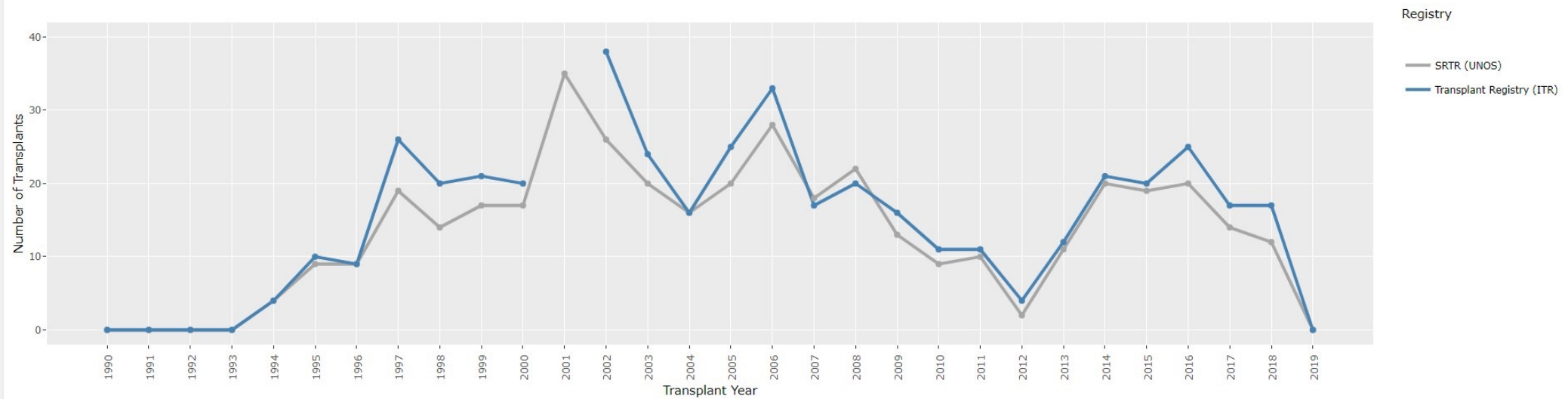
Data current as of: **September 30, 2019**

How to Use This Dashboard: This dashboard displays key information from the Intestinal Transplant Registry for the transplant center mentioned above. Please click on the different titles in the header to access data about:

1. Introduction
2. Center Overview
3. Missing Fields - 2019
4. Missing Fields - Recent Years
5. Action Items for Center
6. Patient List

If you have any questions about this report or the registry, please contact: redcap@terasaki.org

Transplants at this center in ITR by year (blue line)



Only U.S. centers report to UNOS, and the data has not been added for 2018-2019.

Frequently Asked Questions

Questions

When is each ITR form supposed to be filled out for each transplant?

- At the patient's baseline intake, fill out the forms listed under "Baseline" time point.
- At the patient's annual visit for year 1 through year 30, fill out the forms listed under "Annual Visit."
- Upon the patient's death or graft removal, fill out the forms listed under "Status."
- At the time of a clinical event, fill out the forms listed under "Clinical Event."

How should dates be entered into the ITR? What format is correct?

Please use the requested format in the field notes. The correct format should be Month-Day-Year.

If a patient has a transplant and then is re-transplanted at a later date, what forms are completed?

- When the first graft fails, the Graft Removal or Death Form should be filled out for the patient.
- Next, a new Baseline Intake Form for the same patient should be filled out for the second transplant.
- Please enter the "patient ID of previous transplant" on the Baseline Intake Form for the second transplant, so the two transplants can be linked to the same patient.
- These are two different transplant events, so there will be two different patient ids.