# Intestine Transplant Candidate Registration

The Transplant Candidate Registration (TCR) record is generated when a candidate for transplant is added to the OPTN/UNOS waiting list.

If the candidate is already on the waiting list for a transplant, another TCR record will not be generated unless listed by a different center or for another organ type.

The TCR record must be completed within 90 days from the record generation date. See <u>OPTN/UNOS Policies</u> for additional information. Use the search feature to locate specific policy information on Data Submission Requirements.

To correct information that is already displayed on an electronic record, call the UNet<sup>SM</sup> Help Desk at 1-800-978-4334.

#### **Provider Information**

**<u>Recipient Center</u>**: The Recipient Center information reported in Waitlist displays. Verify that the center information is the hospital where the transplant operation will be performed. The Provider Number is the 6-character Medicare identification number of the hospital. This is followed by the Center Code and Center Name.

#### **Candidate Information**

**<u>Organ Registered</u>:** Verify the organ(s) displayed is/are the organ(s) listed for this candidate. If the candidate is listed for more than one type of transplant, both organs should be displayed. Separate records exist for certain multi-organ transplant candidates (e.g. Heart/Lung and Kidney/Pancreas).

**Date of Listing or Add:** The date the candidate was listed or added in Waitlist will display.

<u>Name</u>: The waitlisted candidate's last name, first name and middle initial will be displayed. If it is incorrect, corrections must be completed on the active waitlist. For a candidate who has been removed from the waitlist, the **Last Name**, **First Name** and **MI** fields will display. Corrections may be made directly in the record. These fields are **required**.

**<u>Previous Surname</u>**: If the candidate had a previous surname that is different from the Name entered, enter the previous surname.

**<u>SSN</u>**: Verify the candidate's social security number. If the information is incorrect and the candidate is waitlisted, contact the UNOS Organ Center at 1-800-292-9537.

**Birth Sex:** Report candidate sex (Male or Female), based on biologic and physiologic traits at birth. If sex at birth is unknown, report sex at time of registration as reported by candidate or documented in medical record. The intent of this data collection field is to capture physiologic characteristics that may have an impact on recipient size matching or graft outcome. This field is **required**.

**<u>HIC</u>**: Enter the 9 to 11 character Health Insurance Claim number for the candidate. If the candidate does not have a HIC number, you may leave this field blank.

**DOB:** Verify the displayed date is the candidate's date of birth. If the information is incorrect, correction must be completed on the active waitlist. If the candidate has been removed, reenter

the correct date using the 8-digit numeric format of MM/DD/YYYY. Corrections may be made directly in the record. This field is **required**.

**<u>State of Permanent Residence</u>**: Select the name of the state of the candidate's permanent address at the time of listing (location of full-time residence, not where the candidate is currently waiting). This field is **required**. (<u>List of State codes</u>)

**<u>Permanent Zip Code</u>**: Enter the candidate's permanent zip code (location of full-time residence, not where the candidate is currently waiting). This field is **required**.

**Ethnicity:** The Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity (Office of Management and Budget (OMB) <u>Statistical Policy Directive No. 15</u>) define the minimum standards for collecting and presenting data on race and ethnicity for all Federal reporting. The OPTN collection of ethnicity is aligned to this standard.

OMB defines ethnicity to be whether or not a person self-identifies as Hispanic or Latino. For this reason, ethnicity is broken out into two categories, (1) Hispanic or Latino or (2) Not Hispanic or Latino. Select one ethnicity category or select 'Ethnicity Not Reported' if a category was not self-identified by the person.

This field is required.

**Hispanic or Latino** – A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race.

### Not Hispanic or Latino

Ethnicity Not Reported – Select if person did not self-identify an ethnicity category.

**Race:** The Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity (Office of Management and Budget (OMB) <u>Statistical Policy Directive No. 15</u>) define the minimum standards for collecting and presenting data on race and ethnicity for all Federal reporting. The OPTN collection of race is aligned to this standard. OMB defines race as a person's self-identification with one or more social groups.

An individual can select one or more race categories (1) White, (2) Black or African American, (3) Asian, (4) American Indian or Alaska Native, (5) Native Hawaiian or Other Pacific Islander, or Race Not Reported.

This field is required.

Select one or more race sub-categories or origins. Select 'Other Origin' if origin is not listed. Select 'Origin Not Reported' if the origin was not self-identified by the person.

**White** – A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

European Descent Arab or Middle Eastern North African (non-Black) Other Origin Origin Not Reported **Black or African American** – A person having origins in any of the Black racial groups of Africa.

African American African (Continental) West Indian Haitian Other Origin Origin Not Reported

American Indian or Alaska Native – A person having origins in any of the original peoples of North and South America (including Central America) and who maintains tribal affiliation or community attachment.

American Indian Eskimo Aleutian Alaska Indian Other Origin Origin Not Reported

**Asian** – A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

Asian Indian/Indian Sub-Continent Chinese Filipino Japanese Korean Vietnamese Other Origin Origin Not Reported

**Native Hawaiian or Other Pacific Islander** – A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

Native Hawaiian Guamanian or Chamorro Samoan Other Origin Origin Not Reported

Race Not Reported – Select if person did not self-identify a race category or origin.

<u>**Citizenship**</u>: Select as appropriate to indicate the candidate's citizenship. This field is **required**. (<u>List of Citizenship codes</u>)

**U.S. Citizen:** A United States citizen by birth or naturalization.

**Non-U.S. Citizen/U.S. Resident:** A non-citizen of the United States for whom the United States is the primary place of residence.

Non-U.S. Citizen/Non-U.S. Resident, Traveled to U.S. for Reason Other Than Transplant: A non-citizen of the United States for whom the United States is not the primary place of residence, and who came to the U.S. for a reason other than transplant.

**Non-U.S. Citizen/Non-U.S. Resident, Traveled to U.S. for Transplant:** A non-citizen of the United States for whom the United States is not the primary place of residence, and who came to the U.S. for the purpose of transplant.

Country of Permanent Residence: If Non-U.S. Citizen/Non-U.S. Resident, Traveled to U.S. for Reason Other Than Transplant or Non-U.S. Citizen/Non-U.S. Resident, Traveled to U.S. for Transplant is selected, enter the country associated with the primary place of residence. This field is required.

**Year of Entry to the U.S.:** If the candidate is a Non-U.S. Citizen/Non-U.S. Resident, enter the year the candidate entered the United States. Select the appropriate status from the **ST** Field (**Missing**, **Unknown**, **N/A**, **Not Done**). This field is **required**.

**<u>Highest Education Level</u>**: Select the choice which best describes the candidate's highest level of education. This field is **required**. (List of Education codes)

None Grade School (0-8) High School (9-12) or GED Attended College/Technical School Associate/Bachelor Degree Post-College Graduate Degree N/A (< 5 Yrs Old) Unknown

<u>Patient on Life Support</u>: If the candidate was on life support at the time of listing, select **Yes**. If not, select **No**. If **Yes**, select life support types that apply. If **Other Mechanism, Specify** is selected, enter the type of mechanism in the space provided. This field is **required**.

Ventilator - select only if the candidate was on continuous invasive ventilation Artificial Liver Other Mechanism, Specify

**<u>Functional Status</u>**: Select the choice that best describes the candidate's functional status at the time of listing. This field is **required**. (<u>List of Functional Status codes</u>)

*Note:* The Karnofsky Index will display for adults aged 18 and older.

100% - Normal, no complaints, no evidence of disease

90% - Able to carry on normal activity: minor symptoms of disease

80% - Normal activity with effort: some symptoms of disease

70% - Cares for self: unable to carry on normal activity or active work

60% - Requires occasional assistance but is able to care for needs

50% - Requires considerable assistance and frequent medical care

40% - Disabled: requires special care and assistance

30% - Severely disabled: hospitalization is indicated, death not imminent

20% - Very sick, hospitalization necessary: active treatment necessary

10% - Moribund, fatal processes progressing rapidly

Unknown

*Note:* The Lansky Score will display for pediatrics aged less than 18.

100% - Fully active, normal
90% - Minor restrictions in physically strenuous activity
80% - Active, but tires more quickly
70% - Both greater restriction of and less time spent in play activity
60% - Up and around, but minimal active play; keeps busy with quieter activities
50% - Can dress but lies around much of day; no active play; can take part in quiet play/activities
40% - Mostly in bed; participates in quiet activities
30% - In bed; needs assistance even for quiet play
20% - Often sleeping; play entirely limited to very passive activities
10% - No play; does not get out of bed
Not Applicable (patient < 1 year old)</li>
Unknown

*Note:* This evaluation should be in comparison to the person's normal function, indicating how the patient's disease has affected their normal function.

**<u>Cognitive Development</u>**: (Complete for candidates 18 years of age or younger.) Select the choice that best describes the candidate's cognitive development at the time of listing. (<u>List of Cognitive Development codes</u>)

**Definite Cognitive Delay/Impairment** (verified by IQ score <70 or unambiguous behavioral observation)

**Probable Cognitive Delay/Impairment** (not verified or unambiguous but more likely than not, based on behavioral observation or other evidence)

**Questionable Cognitive Delay/Impairment** (not judged to be more likely than not, but with some indication of cognitive delay/impairment such as expressive/receptive language and/or learning difficulties)

No Cognitive Delay/Impairment (no obvious indicators of cognitive delay/impairment)

#### Not Assessed

<u>Motor Development</u>: (Complete for candidates 18 years of age or younger.) Select the choice that best describes the candidate's motor development at the time of listing. (<u>List of Motor</u> <u>Development codes</u>)

**Definite Motor Delay/Impairment** (verified by physical exam or unambiguous behavioral observation)

**Probable Motor Delay/Impairment** (not verified or unambiguous but more likely than not, based on behavioral observation or other evidence)

**Questionable Motor Delay/Impairment** (not judged to be more likely than not, but with some indication of motor delay/impairment)

No Motor Delay/Impairment (no obvious indicators of motor delay/impairment)

#### Not Assessed

<u>Working for income</u>: (Complete for candidates 18 years of age or older.) If the candidate is physically working and receiving a salary for income, select **Yes**. If not, select **No**. If unknown, select **UNK**.

<u>Academic Progress</u>: (This field is required for candidates less than 18 years of age.) Select the choice that best describes the candidate's academic progress at the time of listing. If the candidate is too young for school or has graduated from high school, select **Not Applicable**, **too young for school/High School graduate or GED**. (List of Academic Progress codes)

Within One Grade Level of Peers Delayed Grade Level Special Education Not Applicable, too young for school/High School graduate or GED Status Unknown

<u>Academic Activity Level</u>: (This field is required for candidates less than 18 years of age.) Select the choice that best describes the candidate's academic activity level at the time of listing. If the candidate is too young for school or has graduated from high school, select **Not Applicable, too young for school/High School graduate or GED**. (List of Academic Activity Level codes)

Full academic load Reduced academic load Unable to participate in academics due to disease or condition Not Applicable, too young for school/High School graduate or GED Status Unknown

**<u>Previous Transplants</u>**: The three most recent transplant(s), indicated on the candidate's validated Transplant Recipient Registration (TRR) record(s), will display. Verify all previous transplants listed by organ type, transplant date and graft failure date.

*Note:* The three most recent transplants on record for this candidate will be displayed for verification. If there are any prior transplants that are not listed here, contact the UNet Help Desk at 1-800-978-4334 or <u>unethelpdesk@unos.org</u> to determine if the transplant event is in the database.

#### Source of Payment:

**<u>Primary</u>**: Select as appropriate to indicate the candidate's source of primary payment (largest contributor) for the transplant. If the source of payment is not yet determined, select **Pending**. This field is **required**.

**Private insurance (commercial Health insurance)** refers to commercial insurance through an employer or affordable care act. It also refers to any worker's compensation that is covered by a private insurer.

Public insurance - Medicaid refers to state Medicaid funds.

**Public insurance - Medicare FFS (Fee-for-Service)** refers to funds from the government in which doctors and other health care providers are paid for each service provided to a candidate. Includes Medicare part A, part B and part D. Medicare part A (hospital) must be in place to be considered primary payer. For additional information about Medicare, see <a href="http://www.medicare.gov/">http://www.medicare.gov/</a>.

**Public insurance - Medicare Part C or Medicare Advantage** Original (Fee for Service) Medicare is assigned to a private plan insurer instead of the federal government. Payments are made based on a montly predetermined date. Sometimes a recipient may receive additional benefits such as prescription drugs. Medicare part A and B must be in place to sign up for Medicare part C or Medicare Advantage. For additional information about Medicare, see http://www.medicare.gov/.

#### Public insurance - CHIP (Children's Health Insurance Program)

**Public insurance - Department of VA** refers to funds from the Veterans Administration.

Self Pay indicates that the candidate will pay for the cost of transplant.

**Donation** indicates that a company, institution, or individual(s) donated funds to pay for the transplant and care of the candidate.

Free Care (Charity Care) indicates that the transplant hospital will not charge candidate for the costs of the transplant operation.

**Pending** is used if the source of payment is not yet determined (Primary only).

**Foreign Government, Specify** refers to funds provided by a foreign government (Primary only) Specify the foreign country in the space provided.

**Public Insurance -TRICARE** Select this option if the patient has TRICARE health coverage.

**Public Insurance - Indian Health Service** Select this option if the patient has IHS health coverage.

**Public Insurance - State Program** select this option if the patient has health coverage through their state.

#### **Clinical Information: At Listing**

<u>Height Date of Measurement</u>: (Complete for candidates 18 years of age or younger.) Enter the date, using the 8-digit format of MM/DD/YYYY, the candidate's height was measured.

**Height:** Enter the height of the candidate at the time of listing in the appropriate space, in feet and inches or centimeters. If the candidate's height is unavailable, select the appropriate status from the **ST** field (**Missing**, **Unknown**, **N/A**, **Not Done**). This field is **required**. (<u>List of Status</u> codes) For candidates 18 years old or younger at the time of listing, UNet will generate and display calculated percentiles based on the 2000 CDC growth charts.

**Weight Date of Measurement:** (Complete for candidates 18 years of age or younger.) Enter the date, using the 8-digit format of MM/DD/YYYY, the candidate's weight was measured.

<u>Weight</u>: Enter the weight of the candidate at the time of listing in the appropriate space, in pounds or kilograms. If the candidate's weight is unavailable, select the appropriate status from the **ST** field (**Missing**, **Unknown**, **N/A**, **Not Done**). This field is **required**. (<u>List of Status codes</u>) For candidates 18 years old or younger at the time of listing, UNet will generate and display calculated percentiles based on the 2000 CDC growth charts.

**<u>BMI (Body Mass Index)</u>**: The candidate's BMI will display. For candidates less than 20 years of age at the time of listing, UNet will generate and display calculated percentiles based on the 2000 CDC growth charts.

**Percentiles** are the most commonly used clinical indicator to assess the size and growth patterns of individual children in the United States. Percentiles rank the position of an individual by indicating what percent of the reference population the individual would equal or exceed (i.e. on the weight-for-age growth charts, a 5 year-old girl whose weight is at the 25th percentile, weighs the same or more than 25 percent of the reference population of 5-

year-old girls, and weighs less than 75 percent of the 5-year-old girls in the reference population). For additional information about CDC growth charts, see <u>http://www.cdc.gov/</u>.

*Note:* Users who check the BMI percentiles against the CDC calculator may notice a discrepancy that is caused by the CDC calculator using 1 decimal place for height and weight and UNet using 4 decimal places for weight and 2 for height.

**ABO Blood Group:** The candidate's blood type will be displayed. If the blood type is incorrect, correction must be completed on the active waitlist. If the candidate has been removed from the active waitlist, you may select the candidate's correct blood type directly in the record. (List of ABO Blood Type codes)

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A
A1
A1B
A2
A2B
AB
B
O
Z (In Utero Only)
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<u>Primary Diagnosis</u>: Select the primary diagnosis for the disease requiring a transplant at the time of listing for this candidate. If the candidate has had a previous transplant for the same organ type, use **Retransplant/Graft Failure** as the primary diagnosis for that organ. If an **Other** code is selected, use the blank provided to specify the **Other** diagnosis. This field is **required**. (List of Intestine Diagnosis codes)

## **General Medical Factors:**

**Diabetes:** If the candidate does not have diabetes at time of listing, select **No**. If the candidate has diabetes, select **Type I** or **Type II**. If the candidate has any type of druginduced diabetes, select **Type Other**. If the candidate has diabetes but the type is unknown, select **Type Unknown**. A patient should *not* be considered as having diabetes based on gestational diabetes only. If this information is unknown, select **Diabetes Status Unknown**. This field is **required**. (List of Diabetes codes)

#### No

**Type I** is defined as a disease in which the body does not produce any insulin, most often occurring in children and young adults. People with Type 1 diabetes must take daily insulin injections to stay alive. Type 1 diabetes accounts for 5 to 10 percent of diabetes.

**Type II** is defined as a metabolic disorder resulting from the body's inability to make enough, or properly use, insulin. It is the most common form of the disease. Type 2 Diabetes accounts for 90 to 95 percent of diabetes.

# Type Other

# Type Unknown

### Diabetes Status Unknown

Any previous malignancy: If the candidate <u>has</u> history of any previous malignant cancer prior to the time of listing, select **Yes**. If the candidate <u>has not</u> had a history of any previous malignant cancer prior to the time of listing, select **No**. If **Yes** is selected, select the type(s) of malignancy. If **Other, specify** is selected, indicate the type of tumor in the space provided. This field is **required**. (List of Adult Malignancy codes) (List of Pediatric Malignancy codes) Skin Melanoma Skin Non-Melanoma CNS Tumor Genitourinary Breast Thyroid Tongue/Throat/Larynx Lung Leukemia/Lymphoma Liver Hepatoblastoma Hepatocellular Carcinoma Cholangiocarcinoma Other, specify

**Total Bilirubin:** Enter the total bilirubin value in mg/dl. If the value is unavailable, select the appropriate status from the **ST** field (**Missing**, **Unknown**, **N/A**, **Not Done**). This field is **required**. (List of Status codes)

#### **Intestine Medical Factors**

**Loss of two or more vascular access sites:** (Complete for candidates 18 years of age or younger.) If the candidate has exhausted two or more vascular access sites at the time of listing, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required** for pediatric candidates.

<u>History of Portomesenteric Vein Thrombosis</u>: If the candidate has a history of portomesenteric vein thrombosis at the time of listing, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required** for pediatric candidates.

<u>Variceal Bleeding within Last Two Weeks</u>: If the candidate has experienced variceal bleeding in the last two weeks, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

**<u>Recurrent Sepsis</u>**: If the candidate has a history of recurrent sepsis, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

**Fungal Sepsis:** If the candidate has a history of fungal sepsis, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

<u>Unmanageable Fluid-Electrolyte Losses</u>: If the candidate has a history of unmanageable fluid-electrolyte losses, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

<u>Non-reconstructible GI Tract</u>: If the candidate has a non-reconstructible GI tract, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

**Public Burden Statement:** The private, non-profit Organ Procurement and Transplantation Network (OPTN) collects this information in order to perform the following OPTN functions: to assess whether applicants meet OPTN Bylaw requirements for membership in the OPTN; and to monitor compliance of member organizations with OPTN Obligations. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this information collection is 0915-0157 and it is valid until

XX/XX/202X. This information collection is required to obtain or retain a benefit per 42 CFR §121.11(b) (2). All data collected will be subject to Privacy Act protection (Privacy Act System of Records #09-15-0055). Data collected by the private non-profit OPTN also are well protected by a number of the Contractor's security features. The Contractor's security system meets or exceeds the requirements as prescribed by OMB Circular A-130, Appendix III, Security of Federal Automated Information Systems, and the Departments Automated Information Systems Security Program Handbook. The public reporting burden for this collection of information is estimated to average 0.27 hours per response, including the time for reviewing instructions, searching existing data sources, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to HRSA Information Collection Clearance Officer, 5600 Fishers Lane, Room 14N39, Rockville, Maryland, 20857 or paperwork@hrsa.gov.