Liver Familial Amyloid Polyneuropathy (FAP) MELD/PELD Initial Exception Score Form

Diagnosis

The following fields, from the candidate's Waitlist record, are read-only. If the information is incorrect, it may be updated on the candidate's Waitlist record.

<u>Transplant Center</u>: Verify the transplant center code is correct.

Name: Verify the candidate's name is correct.

<u>Date of birth</u>: Verify the candidate's date of birth is correct.

Waitlist ID: Verify the candidate's Waitlist ID number is correct.

SSN: Verify the candidate's social security number is correct.

ABO: Verify the candidate's blood type is correct.

<u>Diagnosis</u>: Select the candidate's diagnosis from the drop-down list.

Cholangiocarcinoma (CCA)

Cystic fibrosis (CF)

Familial amyloid polyneuropathy (FAP)

Hepatic artery thrombosis (HAT)

Hepatocellular carcinoma (HCC)

Hepatopulmonary syndrome (HPS)

Metabolic disease

Portopulmonary hypertension

Primary hyperoxaluria

Other specify

<u>Candidate MELD/PELD data</u>: The fields, from the candidate's Waitlist record in the MELD/PELD Data Collection section, are read-only. Click **view details** to expand. Click **hide details** to collapse.

Details

Familial amyloid polyneuropathy (FAP): If familial amyloid polyneuropathy is selected for a candidate, complete the following questions:

<u>Is the candidate actively registered on the waiting list for a heart transplant?</u>: Whether or not the candidate is actively registered on the waiting list for a heart transplant is automatically determined by the system.

What is the candidate's ejection fraction (EF) as measured by echocardiogram?: Enter the percent and date of the echo. Ejection fraction value must be between 1 and 99 percent.

<u>Can the candidate walk without assistance?</u>: If the candidate can walk without assistance, select **Yes**. If not, select **No**. This is a **required** field.

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<u>Has a transthyretin (TTR) gene mutation been confirmed?</u>: If a transthyretin (TTR) gene mutation has been confirmed, select **Yes**. If not, select **No**. This is a **required** field.

<u>Does the candidate have a biopsy-proven amyloid?</u>: If the candidate has a biopsy-proven amyloid, select **Yes**. If not, select **No**. This is a **required** field.

Results

Review results: The candidate's result details display.

Score

<u>Policy score for candidates meeting standard criteria</u>: The policy score for candidates meeting standard criteria displays.

Please request an exception score: Select an exception score for the candidate:

Equal to the policy assigned score for candidates meeting standard criteria Score adjusted from the median MELD at transplant (MMaT)

Less than MMaT (the number must fall between 1 and 20)

Equal to MMaT

More than MMaT (the number must fall between 1 and 20)

MELD 40

PELD 40 or higher (for pediatric candidates; the number must fall between 40 and 99)

<u>Justification narrative</u>: Enter text justifying the requested higher MELD or PELD score. 8000 character limit.

Confirm

<u>Transplant physician name</u>: Enter the transplant physician's name. This is a **required** field. <u>Transplant physician NPI</u>: Enter the transplant physician's NPI number. The NPI must be 10 digits. This is a **required** field.

Email decision to: Enter at least one and up to three email addresses to receive notification of the outcome of the vote. Including up to three email addresses may be important to account for time off or out-of-office. This is a **required** field.

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

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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.