

Guidance to Liver Transplant Programs and Regional Review Boards for MELD/PELD Exceptions Submitted for Neuroendocrine Tumors and Polycystic Liver Disease

Strategic Plan

- Goal: Increase Access to Transplants
- Objective: Reduce Geographic Disparities in Access to Transplantation

Standardized MELD exception criteria across the country would provide better access to transplant for those most in need and would help eliminate some of the geographic inequities that arise from each Region using its own criteria (or no criteria).

Purpose

- Document contains specific recommendations for use by the liver Regional Review Boards (RRBs) to evaluate exceptional case requests for candidates with neuroendocrine tumors (NET) and polycystic liver disease (PCLD)
- Intent : promote consistent review of these diagnoses throughout the country
- A continuation of previous efforts to develop standardized criteria for exceptional diseases and conditions.

BACKGROUND

- MESSAGE Conference (March 2006) and Paper(s) (December 2006)
- Created Standard Diagnoses for Hepatopulmonary Syndrome (HPS), Cholangiocarcinoma (CCA), Cystic Fibrosis (CF), Familial Amyloid Polyneuropathy (FAP), Primary Hyperoxaluria (PH), and Portopulmonary Syndrome (PPS)
- Initially Submitted to RRBs as Guidance
- Included in OPTN Policy in November 2009
- Committee Began New Exception Diagnosis Review in 2013

MELD Exception Requests, May 1, 2012 - April 30, 2013

Initial Requests Only (non-HCC)

DIAGNOSIS	Frequency	Percent of total
Familial Amyloidosis	28	2.2
Hepatic Artery Thrombosis (HAT)	61	4.7
Hepatopulmonary Syndrome	204	15.8
Portopulmonary Hypertension	68	5.3
Primary Oxaluria	14	1.1
CCA*	63	4.8
Other specify	857	71.0
Neuroendocrine Tumor (NET)	22	1.7
Polycystic Liver Disease (PCLD)	53	4.1
Primary Sclerosing Cholangitis (PSC)	101	7.8
Hyponatremia	142	11
Hydrothorax	42	3.2
Ascites	41	3.2
(Remaining Other Specify)	456	35.2

Small but increasing

MELD-Na should eliminate

Very Heterogeneous

Process / Recommendations

- Committee members reviewed the medical literature for these diagnoses when drafting guidelines for these diagnoses
- Criteria for RRBs to Consider
- No Score Assignments
 - Limited Mortality Risk/Natural History Data
- Guidelines for NET and PCLD Submitted at June Board Meeting
- Specific details included in the Board Materials
- If approved, guidelines will be made available to RRBs following the Board Meeting

Next Steps

- Guidelines for PSC still being developed - to be submitted to the Board in November 2014
- May Lead to Future Policy Proposal(s) for NET, PCLD, PSC