

National Liver Review Board (NLRB)

Frequently asked questions for candidates and caregivers

The process for evaluating and assigning an exception score for liver transplant candidates changed May 14, 2019. Previously, if your MELD or PELD score did not fully address your need for a liver transplant, a review board from your region would evaluate and decide on any request to assign you a custom exception score. The new review board is a national one, not a regional review board.

In addition, liver candidates with certain medical conditions receive a standard exception score – a set value that is usually higher than their calculated MELD or PELD score. The new policy sets new standard exception scores for some patients' conditions. Some standard scores will stay the same as they were before the new policy, while others will be different.

So what changed?

There are a few changes to the system:

- A national, not a regional, board will review and assign non-standard exception scores. Depending on your age and medical condition(s), the request would go to one of three boards that review specific criteria:
 - o One national board is for pediatric patients – those who are younger than age 18 when they are listed for a transplant.
 - o A second board is for adult candidates with any condition other than hepatocellular carcinoma, also called HCC.
 - o A third board is for candidates who have HCC.
- Some of the standard exception scores will change. Your care team can discuss more specifically with you how they may apply to your condition.
- Most of the time, exception scores will be compared to the median MELD or PELD score at transplant. A median is the statistically calculated “midpoint” score over a range of all recently performed transplants in an area surrounding the transplant hospital. If the median score is 28, it means half of the recipients were transplanted at a 28 or lower, while half were transplanted at a score of at least 28. Most adult candidates will have a standard exception score three points lower than the median MELD.
- The national review board will consider, on an individual medical basis, whether the exception score may be lower than, the same as, or higher than, the median MELD or PELD score.

What didn't change?

The overall processes for assigning standard exceptions did not change. Your transplant team sends information to UNOS confirming that you meet medical criteria for a standard exception. If so, you will receive the assigned score. These exceptions must be renewed periodically to ensure you still qualify. The overall process of reviewing non-standard exceptions also stayed the same, even though reviewers on the board may now come from anywhere in the country. The reviewers consider only medical information about your condition. They do not get information identifying you, the hospital at which you are listed, or even the part of the country where you live.

National Liver Review Board (NLRB)

Frequently asked questions for candidates and caregivers

The review board will approve or decline the exception score requested. For a request that is denied, your team may appeal the decision for further consideration.

What led to this new system?

Regional review boards in different areas of the country could use different criteria for considering requests or award an exception score that was higher or lower than scores granted elsewhere. Exception scores also used to increase automatically over time based on time waiting instead of clinical decline; this could also increase differences in transplant scores. The national board will ensure that cases are reviewed by common criteria and the assignment of exception scores will be more uniform across the country.

In addition, median MELD and PELD scores at transplant differ considerably in some areas of the country. For example, an exception MELD of 30 may represent very high transplant priority in some areas, while elsewhere most candidates are transplanted at a higher score. The indexing of exception scores to a median MELD or PELD at transplant will help ensure the assigned score is more proportional to the candidates' needs and accommodates the needs of candidates who rely on calculated MELD or PELD scores.

If I have an exception score at the time of the policy change, will it change at that time?

For most candidates with existing exception scores as of May 14, 2019, their score was converted on that day to the new criteria. Some exception scores that are considerably higher or lower than most median scores will stay the same until those scores expire or need to be renewed. The following chart shows how existing exception scores will be managed on May 14.

Candidate Age	Diagnosis	Current exception score	Exception score after conversion
At least 18 at registration	Any	40	40
At least 18 at registration	Any (except primary hyperoxaluria)	22-39	Median MELD at Transplant minus 3
At least 18 at registration	Primary hyperoxaluria	22-39	Median MELD at Transplant
At least 18 at registration	Any	Less than 22	No change to score
At least 12, and less than 18 at registration	Any	40	40
At least 12, and less than 18 at registration	Any (except primary hyperoxaluria)	22-39	Median MELD at Transplant
At least 12, and less than 18 at registration	Primary hyperoxaluria	22-39	Median MELD at Transplant plus 3
At least 12, and less than 18 at registration	Any	Less than 22	No change to score
Less than 12	Any	40 or higher	No change to score
Less than 12	Any (except primary hyperoxaluria)	Less than 40	Median PELD at Transplant
Less than 12	Primary hyperoxaluria	Less than 40	Median PELD at Transplant plus 3

Your exception score must be renewed on a periodic basis if you remain eligible for it. The new criteria will continue to apply to any renewed exception score.

National Liver Review Board (NLRB)

Frequently asked questions for candidates and caregivers

Could my exception score go down? If so, how could that affect my chances to get a transplant?

With the new system, your score could stay the same, or it could change based on the new criteria. It could either increase or decrease. The new criteria are meant to balance the transplant opportunity for exception candidates along with those who use a calculated MELD or PELD score.

Also, since the exceptions are based on the median MELD or PELD at transplant, your score could increase or decrease based on changes to the median score over time. The median will be recalculated every six months to ensure your score is compared accurately.

Your transplant team is in the best position to discuss with you whether your exception score may change and, if so, how this is likely to affect your treatment and your opportunity for a transplant.

If I list at a different center, would my exception score be different?

It could be different from one hospital to another, based on the median score at that hospital. A key goal of the system is to reduce variation in median transplant scores across the country. The Organ Procurement and Transplantation Network (OPTN) will continue to study the effects of the policy and seek to improve it for the benefit of all candidates.

Is there anything I need to do?

You don't need to do anything different, such as fill out new forms. Do keep in mind that if your score is subject to a renewal, and you still qualify for an exception, your transplant team will need to re-submit information by the renewal date. In that case, stay in touch with your transplant team to know when a renewal is due and whether they need any new information or test results from you.

How can I learn more?

Your transplant team is the first and most complete source of information relating to your care and treatment. They can discuss how the new system may apply to you specifically.

For more detail about the new boards, and the guidelines and criteria they will use, visit the [website](#) of the Organ Procurement and Transplantation Network (OPTN).

You may also contact OPTN Patient Services by e-mail (patientservices@unos.org) or phone (888-894-6361).