Sample letter for candidates with MELD or PELD exception scores

[Please note: This is a sample letter that liver program staff can consider as a resource for notifying transplant candidates. You may modify or update with additional information specific to your program or to the candidates you are notifying.]

Key changes are planned for processes to approve or extend MELD and PELD exception scores for liver transplant candidates nationwide.

The key changes to the exception score process are described below. Your medical condition, and individual details about your current score, may influence whether or how these changes may apply to you. We are happy to discuss details with you on an individual basis.

If you have a standard exception – a set value of MELD or PELD points assigned to you based on your medical condition – some new criteria may apply, and the standard score may be different in the future. Most standard exception scores will be converted to the new criteria on April 30. The criteria will also apply to any patient who gets a newly approved standard exception score after that date.

Under the new criteria, most standard 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. If the median score is 28, it means half of local recipients were transplanted at a 28 or lower, while half were transplanted at a score higher than 28.

Most standard exception scores for adult candidates will be set at three points below the median MELD score at transplant for our area. So, for example, if our median MELD score is 28, most standard exception scores will be set at 25. The median score will be recalculated twice a year, and any adjustments to the exception score would be made at that time.

The new standard exception score may be higher than, lower than, or the same as the score you have currently. The new score will not automatically increase over time, as some scores have done under the current policy. The goal in comparing it to the local median score is to balance the priority of exception candidates with that of patients who are prioritized based on their calculated MELD or PELD score. If our transplant team believes your condition is more urgent than the standard score and you may need a higher exception score, we will apply to the review board (described below) for a non-standard score assignment.

If you receive a standard exception score because you have hepatocellular carcinoma (HCC), you would continue to receive exception points six months after first qualifying for the exception. This is the same as in the previous policy and will not change.

If you receive an exception score that is **not** a standard point assignment, those decisions will continue to be made by a review board of liver transplant clinicians. Up until April 30, 2019, the review board has been drawn from transplant professionals within our region of the country. After that date, the reviewers will be drawn from a national pool of liver transplant professionals. We call this the National Liver Review Board, or NLRB.

Although this is now a national board, the way they review and decide on score requests will be largely the same as before. The reviewers consider only medical information about your condition. They do not get information identifying you or even naming the hospital where you are listed.

If you qualify for a standard exception but we request that you get additional priority, the reviewers will consider that request in the context of the median MELD or PELD at transplant. If you do not qualify for a standard exception but are sicker than your MELD or PELD score indicates, we ask the review board to assign a custom score that compares your need fairly with the needs of other patients in our area.

The review board will approve or decline the exception score requested. If the request is denied, our transplant team will consider whether to appeal the decision for further consideration.

A <u>frequently asked questions (FAQ) document</u> is available to address some additional questions you may have. And as always, we are glad to discuss your current condition and the best options for treating you.

In addition to the changes to the review board, a new liver distribution policy also will take effect April 30. This new system will base the organ offer process on a more consistent set of distances between the donor hospital and the transplant hospital. Illustrations and an animated guide to the new sequence of organ offers is available <u>here</u>.