



## URGENTLY CALLING FOR YOUR COMMENTS ON UNOS PROPOSAL FOR PSC EXCEPTION POINTS IN MELD SCORE!

Dear PSC Community,

We have a unique opportunity to make our voices heard and to bring about an important change. This is an **urgent** call to action. PSC Partners supports the proposed UNOS policy change. Every comment by PSC patients and caregivers is important. Add your voice **today!**

**Background on MELD<sup>1</sup> & PELD scores and PSC:** Over and over, our community helplessly witnesses the tragic outcomes that can arise from the discrepancy existing between a PSCer's MELD score and the severity of their illness. By the time PSC patients reach a high MELD score, they may be too sick to receive a transplant.

**New data:** Recent statistics show that the dropout rate of PSC transplant candidates with a MELD or PELD score **greater than 37** is substantially higher for PSC patients than for other listed liver patients ("dropout" refers to death or to being too sick to be transplanted). This data confirms what we as patients have long observed.

The National Liver Review Board (NLRB) is recommending a change in the policy for exception points regarding the frequency of hospital admission and the location of admission. We need as many PSC patients and caregivers as possible to write to the NLRB now voicing support.

For PSC exception points, currently: PSC patients receive exception points only after they are ***admitted to the ICU two or more times in the last three months for hemodynamic instability requiring vasopressors***, in addition to other requirements which are not changing at this time.

Proposed policy change: PSC patients receive exception points only after they are ***admitted to the hospital two or more times within a one-year period for a documented blood stream infection or evidence of sepsis including hemodynamic instability requiring vasopressors***.

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<sup>1</sup> Terms and abbreviations are defined on the last page

The proposed definition includes details regarding sepsis, which is what causes the hemodynamic instability (low blood pressure). This is treated by vasopressors (medication to increase blood pressure).

The Public Comment Proposal: Updating National Liver Review Board Guidance and Policy Clarification from the OPTN Liver and Intestinal Organ Transplantation Committee can be read here:

[https://optn.transplant.hrsa.gov/media/4344/nlrb\\_guidance\\_policy\\_clarification\\_pc\\_proposal\\_draft.pdf](https://optn.transplant.hrsa.gov/media/4344/nlrb_guidance_policy_clarification_pc_proposal_draft.pdf)

PSC Partners supports these proposed policy changes and will submit their comment to the NLRB.

**Call to action:** The NLRB has invited public comment on this proposal. This is your chance to comment on this proposed policy change that would potentially decrease the inequity created by the MELD and PELD scores for PSC patients waiting for a liver transplant.

The NLRB is asking, “Do you support the proposed changes to PSC/SSC (secondary sclerosing cholangitis) guidance?”

**Individual comments** are meaningful and important to the NLRB, which reviews all comments. Suggestions include:

- Clearly state your support that PSC transplant candidates receive exception points if they are admitted to the hospital two or more times within the last year
- Make your entry **unique** by including any of the following:
  - share your story, or where you are in your PSC journey
  - describe what you’ve observed other PSCers experience
  - discuss how the MELD or PELD score can change over time for PSCers
  - if possible, include specific details to help the NLRB understand the effects of PSC on transplant candidates

**Deadline:** You have until **March 23<sup>rd</sup>** to express our community’s urgent need for change in liver allocation for PSC. Please ask your friends and family to write in, as well. The more people who send a response, the greater the chance the NLRB will adopt this policy change, which is an exciting first step to address the MELD/PELD disparity for PSC transplant candidates.

- **To provide feedback (your comments), visit <http://bit.ly/UNOSComment>**
  - For member type, PSC patients and caregivers should select **Patient**
  - Then indicate Relationship to Transplant by checking **Candidate or Candidate Family**
  - This includes all PSC patients, listed or not, as well as post-transplant, and those who were dropped off the transplant list
- The OPTN Liver and Intestinal Organ Transplantation Committee presentation slides, “Updating National Liver Review Board (NLRB) Guidance and Policy

Clarification,” can be viewed here: <http://bit.ly/UNOSMoreInfo>. You can also read the full proposal and see comments from others.

Thank you for participating in this important public comment period. Be sure to send in your comment as soon as possible, and before the **March 23<sup>rd</sup>** deadline. Questions? Email us at [contactus@pscpartners.org](mailto:contactus@pscpartners.org).

### Definition of Terms:

- **Candidate:** An individual on the organ transplant waiting list
- **Guidance Documents:** Documents that provide more information to transplant programs and NLRB members to use when making decisions on exception request
- **Model for End-Stage Liver Disease (MELD):** The scoring system used in allocation of livers to candidates who are at least 12 years old
- **Pediatric End-Stage Liver Disease (PELD):** The scoring system used in allocation of livers to candidates who are under 12 years old
- **Standardized exception:** An exception with criteria outlined in policy that is automatically approved when submitted and is not reviewed by the NLRB
- **National Liver Review Board (NLRB):** A review board of members drawn from a nationwide pool of liver transplant physicians and surgeons, who review exception requests from transplant programs for candidates whose automatically calculated model for end-stage liver disease (MELD) score or pediatric end-stage liver disease (PELD) score does not accurately reflect the candidate’s medical urgency for transplant
- **OPTN:** Organ Procurement and Transplantation Network
- **Primary Sclerosing Cholangitis (PSC):** A rare disease that causes scarring in the bile ducts
- **Secondary Sclerosing Cholangitis (SSC):** A chronic disease similar to PSC caused by a known condition