

QUESTIONS TO CONSIDER

PRIOR TO A LIVER TRANSPLANTATION FOR MSUD

Transplant Process & Evaluation

- What are the overall benefits and risks of a liver transplant for MSUD?
- What tests and procedures will be done during the evaluation process?
- How is it determined if one is a candidate for liver transplantation?
- How long do you anticipate the wait time for a transplant to be at your center?
- Does the liver transplant team have experience performing surgery on MSUD patients? If so, what is the success rate?
- Do all liver transplant centers have the resources to perform a transplant on someone with MSUD?
- Can I (or my child) be listed at numerous transplant centers?
- How long will the new liver last?
- What type of transplant, living, donor, or domino, will be done?
- Who in my family can be a donor?
- At what age can a liver transplant be done?
- Do I (or my child) need to be well/healthy to have a liver transplant?

Surgery & Recovery

- How long is liver transplant surgery typically?
- What is the expected recovery time after surgery? (length of time in ICU and hospital)
- What can I expect after surgery? (ventilator, medical equipment, wounds)
- What are the immediate risks of surgery?

- What support system is available after the surgery?
- Do I need to plan for housing near the transplant center?
- Are there support programs or resources for caregivers?

Medication & Long-Term Health

- What medications will I (or my child) need to take after the transplant?
- What are the potential side effects of these medications?
- Will these medications need to be taken for life?
- How will the transplant team manage potential infections/complications?
- What are the long-term risks of liver transplantation and immunosuppression?
- Does the liver transplant prevent MSUD crises or am I (or my child) still at risk?
- How frequently will I (or my child) need to have blood drawn after surgery?
- How often will I (or my child) need to return for follow up office visits?
- Does the transplant have an impact on cognitive function?

Support & Lifestyle

- How will the transplant affect my (or my child's) ability to return to daycare, school, or work?
- Will I (or my child) need to continue seeing a metabolic physician or dietician?
- Will the transplant affect my (or my child's) ability to have children?
- Are there animals that should be avoided post- transplant?
- What are the recommendations for swimming in various bodies of water post-transplant?
- Who manages a non-transplant illness after I (or my child) is transplanted?

- Will I (or my child) need special vaccinations after the transplant?
- After transplantation are antibiotics needed before dental procedures?
- Will I (or my child) need to monitor amino acid levels post-transplant?
- What lifestyle changes will I need to make after the transplant?
- Will I (or my child) have any dietary restrictions after transplantation?
- Are there any activities, exercises or sports limitations?
- Are there support groups or resources for patients and families navigating the transplant journey?
- Does my insurance cover the surgery, medications, and follow-up appointments?