Informed Consent for Liver Transplant Evaluation Process

The evaluation process begins when you are first identified as a potential transplant candidate in the Hartford Hospital Liver Transplant Program and continues until a decision is made and you are either listed or declined for listing for a liver transplant.

This document is to help you be informed of the steps in a liver transplant evaluation. It is part of what we call the "informed consent process". It is important that you read and understand this document before you sign it. You should ask questions about any information that you do not understand. In fact, we expect and encourage questions throughout your transplant experience.

EVALUATION PROCESS

An evaluation for a liver transplant involves having many tests, procedures and meeting with members of the Transplant Team. You may also have visits with other health care providers. All these consultations, tests and procedures will help us decide if a liver transplant is the right treatment for you. It will also help us to know if you are well enough to have a liver transplant which is considered major abdominal surgery. These tests will also help us know if there is any other treatment besides a liver transplant that can help you.

TRANSPLANT TEAM MEMBERS

The professionals who make up the Transplant Team come from different specialties to make sure to address the many issues experienced by a patient requiring a liver transplant. This team is referred to as the "Multidisciplinary Transplant Team". The members of this team include:

- **The Hepatologist** is a medical doctor with expertise in gastroenterology who specializes in liver disease. The hepatologist will assist in the medical management of your liver disease. They are part of the multidisciplinary team that will determine if you are medically suitable for a transplant.

- **The Transplant Coordinator** is often an individual with a nursing background who provides education regarding the transplant evaluation process, listing and waiting for transplant and required follow-up care. They will explain the patient responsibilities before and after transplant. This meeting is intended to provide you with an opportunity to ask questions and to become fully informed about the liver transplant process. The coordinator is your **advocate** throughout the transplant process. You are encouraged to bring family members and significant others to this meeting.

- **The Transplant Surgeon** is a surgeon with special training and expertise in liver transplantation and will meet with you after your testing is done and discuss the appropriateness of a transplant based on the information obtained during your evaluation. The surgeon will also discuss the significance of undertaking a liver transplant, the various types of livers available, the risks of the surgery and the possible complications associated with the transplant surgery.

- **The Transplant Social Worker** is a licensed social worker with special training in transplant issues and will meet with you to evaluate your ability to cope with the stress of transplantation and your ability to follow a rigorous treatment plan, both before and after transplantation. The social worker will also help you identify your support network and coping strategies. If you need assistance in these areas, they will work with you to try and find what is available to you.
• The Financial Coordinator has special training in the financial issues associated with transplant and will discuss the costs associated with your transplant and with the medications you will require after transplant. They will be sure you understand your insurance coverage. It is important that you understand the costs that may not be covered by insurance. It is also very important that any changes in insurance coverage is reported to them immediately so that you do not risk being placed on a financial hold for transplant.

• A Psychiatrist is the physician who will conduct a more in-depth psychiatric evaluation and assessment if our social worker or other physician members of the Team feels this would be appropriate. Some patients with a history of drug or alcohol abuse may be required to participate in a formal rehabilitation program. All patients sign a Drug and Alcohol Contract prior to listing. Patients with recent substance abuse must meet abstinence requirements prior to and after transplant listing.

• The Transplant Dietitian has special expertise in the nutritional issues associated with liver disease and will perform a detailed nutritional assessment and provides nutrition education to patients. Most people with end stage liver disease have problems meeting their nutritional needs and maintaining muscle mass because of their illness.

• The Transplant Pharmacist has knowledge of the multiple medication requirements of transplant patients and will review all of your medications throughout the transplant process. They look for medication interactions and may suggest changes to maximize results or minimize side effects. They are also available to both patients and staff as a resource.

• Some patients may be referred to another specialty physician for consultation. For example, a nephrologist (kidney doctor), pulmonologist (lung doctor) or cardiologist (heart doctor). Even if you are seeing a local specialist in your community, unless they are on staff at Hartford Hospital, they would not be available to care for you during your admission. This is why we will often have you see one of our specialists who understand the unique needs of liver transplant patients and can follow you in the hospital. Be assured we will work with your community physicians to provide you with the best care possible.

EVALUATION TESTS

Many different tests are done to determine if you are a suitable transplant recipient. After completing the evaluation process the members of the Multidisciplinary Transplant Team will meet to present your results and determine if you meet the Hartford Hospital selection criteria for placement on the United Network for Organ Sharing (UNOS) Liver Wait List.

TRANSPLANT SURGERY

All types of surgery carry risks. We will only perform your liver transplant when we believe that the benefits to your health outweigh the risks. These risks can be divided into short-term and long-term. Liver transplants have about a 90% success rate. The data specific to our center will be provided to you.

Short-Term Risks of Liver Transplantation

1. Infections
2. Acute Rejection
3. Technical complications (bleeding, bile duct or vascular complications)
4. Re-operation(s)
5. Death
6. Delayed function or non-function of the liver
7. Other

Long-Term Risks of Liver Transplantation

1. Recurrent liver disease or cancer (recurrent or new onset)
2. Chronic Rejection
3. Infection
4. Death
5. Other

Patient Initials___________________
Each of these risk factors has a specific type of treatment and, if complications do occur, we promise to discuss your options and give you the best treatment for your specific situation.

**POST-SURGICAL CARE AND RECOVERY**

After the surgery you will be taken to the intensive care unit where you will be closely monitored. You will be on a machine to help you breathe and you will have many tubes and drains in place. Intermittent pressure boots or sleeves around your legs will be used to prevent blood clots.

Immediately following the surgery, you will experience pain. This will be carefully monitored and controlled. The goal of pain control is to keep you as comfortable as possible so you can move, take deep breaths and begin the recovery process.

When your medical condition has stabilized you will be transferred to the transplant floor. Your length of stay in the hospital will depend on the rate of your recovery. You will remain in the hospital as long as your physicians feel hospitalization is necessary. Most patients stay in the hospital for a period of 7 to 14 days. The hospitalization time varies depending on the severity of your illness prior to transplant or complications after surgery. You may benefit from a stay at the rehabilitation unit for additional physical therapy to regain your strength and level of function prior to discharge home.

After you leave the hospital you will still be recovering. For the first 4-6 weeks you will have some restrictions on your daily activities. During the recovery period the transplant team will closely monitor your progress. You will require life-long follow up and must make yourself available for examinations, laboratory tests and scans of your abdomen to see how well your transplanted liver is working. Biopsies may be done routinely and as needed to diagnose possible complications including rejection or recurrent liver disease.

The Transplant Team will see you regularly for three to six months post-transplant. Every effort is made to transition your routine medical care to your primary care physician. However, you will be followed in the Transplant Clinic for life. For most patients this involves frequent lab work (usually every three months for life) and a yearly clinic visit. Patients who develop complications may need to be seen more often by the Transplant Team.

I understand that after transplant, I will be asked to return to the transplant clinic frequently and have lab tests and or other diagnostic procedures to monitor how well my transplant is working. I understand that it is my responsibility to notify the Transplant Center when I become aware of any problems I may have that would prevent me from keeping my appointments or taking my medicines.

I understand that I will be taking medications after transplant to suppress my immune system and prevent rejection. I understand that I will have to take some of these medications every day at the same times and that I should never change the dose(s) on my own. I understand that I will be taking these drugs for as long as the transplant is functioning, and in some cases even if the transplant fails. I understand that I will be taking many different drugs every day. I understand that many people experience side effects from their anti-rejection drug and it is my responsibility to report any side effects that I may experience to my transplant team.

**ALTERNATIVE TREATMENTS**

Alternative treatment therapies may be available for your medical condition. Please feel free to discuss your condition and any possible alternative therapies with your Transplant Team.
POTENTIAL MEDICAL/PSYCHOSOCIAL RISKS

I understand that bleeding during or after surgery may require blood transfusions or blood products that can contain bacteria and viruses that can cause infection. Although rare, these infections include, but are not limited to, the Human Immunodeficiency Virus (HIV), Hepatitis B Virus (HBV), and Hepatitis C Virus (HCV).

I understand there are other risks associated with liver transplants. Infections from bacteria, viruses, or fungi, acute rejection, and side effects from drugs that suppress the immune system are all possible complications. Side effects from immune-suppressing drugs include kidney problems, gastrointestinal complaints, blood count abnormalities, nerve damage, high blood pressure, weight gain, diabetes, and others. There may be a need for surgeries, and other procedures, or a prolonged intensive care unit or hospital stay after a liver transplant.

I understand there is a slight increase in the risk of certain kinds of cancer (including skin cancer and post-transplant lymphoproliferative diseases or lymphoma) because of the immunity-suppressing medications. There are non-surgical risks associated with liver transplant. I understand there have been cases of recipients having difficulty adjusting to the transplant experience. If I find that I am suffering from fear, anxiety, bad dreams, depression, or guilt about the donor, I will report this to the transplant team.

NOTIFICATION OF MEDICARE OUTCOME REQUIREMENTS NOT BEING MET BY CENTER

Specific outcome requirements need to be met by transplant centers and we are required to notify you if we do not meet those requirements. Currently, the Hartford Hospital Adult Liver Transplant Program ☐ meets all requirements for transplant centers ☐ does not meet the following requirements.

If you have your transplant at a facility that is not approved by Medicare for transplantation, your ability to have your immunosuppressive drugs paid for under Medicare Part B could be affected.

ORGAN DONOR RISK FACTORS

You should be aware that all donors are screened for communicable diseases or problems, such as cancer, that may affect the liver and your health. There is no guarantee as that all contagious diseases or problems have been detected. There may be unforeseen factors including undetected cancer or undetectable infectious disease that may affect the success of your transplant or your health. These include; HIV, Hepatitis B virus, Hepatitis C virus, malaria or other bacterial, viral or fungal infections. There are other factors related to the specific organ donor, such as the donor's history, the donor's age and condition of the donated organ that can affect the success of the transplant and your health. The surgeon will discuss the specific donor risk factors with you in detail as part of your decision to consent to the transplant surgery.

RIGHT TO REFUSE TRANSPLANT

You always have the option not to undergo transplantation and can choose to be removed from the list. If you choose not to have a transplant, your option is to continue with medical management. Keep in mind there is no guarantee that another organ will become available to you. I understand that the suitability of donor organs accepted for transplant is determined by the transplanting physician(s). I understand that I have the right to refuse transplantation.

FINANCIAL IMPLICATIONS

I understand that insurance may pay for part of my transplant expenses. I understand that medications after transplant are not free, and my insurance may pay for part of my transplant medicines. I will be responsible to pay for copayments or medications and services not covered by my insurance. I understand that I need to keep my transplant center’s financial coordinator informed of any changes in insurance coverage(s) or problems that may cause me to be unable to pay for care and/or medication. I understand that if my transplant is not provided in a Medicare approved transplant center, it could affect my ability to have my immunosuppressive drugs paid for under Medicare Part B. I understand that Hartford hospital transplant program is an approved transplant facility for liver organ transplantation. I understand that after you have a liver transplant, health insurance companies may consider you to have a pre-existing condition and refuse payment for medical care, treatments or procedures. After the surgery, your health insurance and life insurance premiums may increase and remain higher. In the future insurance companies could refuse to insure you.

Patient Initials__________
You also have the right to notify the Organ Procurement and Transplantation Network at 1-888-874-6361, if you have any concern or grievance about the Hartford Hospital Transplant Program.

**General**

*In addition to the information provided in this document, I have been informed and have received information about wait time transfer and multiple listing and the possibility of receiving a living donor liver transplant.*

*I will receive a letter of notification concerning my status at the end of this evaluation process indicating that either:

a. I have been accepted and am active on the UNOS waitlist

b. I have been conditionally accepted and placed on hold status on the UNOS waitlist, pending completion of evaluation or treatment

c. I am not an acceptable candidate for transplantation and the reason(s) for this decision*

*I understand that the Hartford Hospital Liver Transplant Program may remove a candidate from the waitlist for changes in their medical condition or inability to comply with medical care.*

*I have received this information from the Transplant Team. I have been provided an opportunity to read the information and ask questions. I understand the information that has being provided to me. I also consent to have my photograph taken and scanned into my electronic chart in the Liver Transplant Office.*

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