

AMERICAN LIVER FOUNDATION PATIENT REGISTRY

What is the American Liver Foundation Patient Registry?

The American Liver Foundation Patient Registry is the first-ever patient registry for all types of liver diseases. It will help provide researchers with a better understanding of liver diseases, the impact of current treatments, and how liver disease affects patients. Until now, there has not been one central place where researchers interested in liver disease can access information on a patient's disease history and more importantly, how patients are managing their disease and its often-debilitating symptoms and associated conditions such as diabetes, heart disease and obesity. With more than 100 different types of liver disease, it is imperative that researchers have access to this kind of information to help discover better treatments and cures.

Who Can Participate?

The American Liver Foundation Patient Registry is voluntary and open to any patient with liver disease, 18 years of age or older, in the U.S. If you decide to join, we will gather data about your disease by asking you to answer questions through a survey. We will combine your answers with those from other participants and researchers will be able to begin using the anonymous data for different research purposes.

How Does it Work?

Powered by EmpiraMed's PRO Portal, the American Liver Foundation Patient Registry is designed to be easy to use. You will know what you are working on, where you are in the process and how long it will take you to complete the survey. The PRO Portal also automatically saves your work so you don't need to worry about losing information, or your place, if you have to stop in the middle of a survey.

What Will I Do?

Share your experience with liver disease! After registering, you will be asked to complete an initial online survey. The survey will ask about:

- Your history of liver disease(s)
- How you manage/treat your disease and symptoms
- Other medical conditions relevant to your liver disease
- Lifestyle choices which may influence your liver health
- Additional information about you

Once completed, you may use your PRO Portal to report changes in your condition. You will receive notifications when new surveys are available and you may be eligible to participate in additional, optional, research activities.

Why Should I Participate?

Your participation helps provide researchers with a better understanding of liver diseases, the impact of current treatments and how your liver disease affects YOU! It was created to collect important data about liver diseases from the patient's perspective.

How Do I Register?

Start changing the face of liver disease today! Scan the QR code below or visit liverpatientregistry.org to register now!

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For questions about liver wellness and disease, or for emotional support to patients at the point of crisis and information on local resources including physician referrals, please contact our Helpline at 1-800-465-4837.

