

American Liver Foundation **PATIENT REGISTRY**

QUICK START GUIDE

Thank you for registering for American Liver Foundation's (ALF) Patient Registry. 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.

WHAT CAN I EXPECT?

The PRO Portal is easy to use. It easily tells you what you are working on, how long it will take and where you are in the process. The PRO Portal also saves your work automatically, so you don't need to worry about losing entries if you stop mid-way. Your privacy is important to us - any information shared within the portal is safe and secure, and data shared with researchers will be de-identified and anonymous.

WHAT WILL I DO?

Share your experience with liver disease! After registering, you will be asked to complete an online survey. It will take about 30 minutes to complete, and you do have the ability to pause and return at a later time, if needed. 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 the "Diary Buttons" in your PRO Portal to report changes in your condition. You will also receive notifications for when new surveys are available. If you choose to participate in a new survey, you simply complete the survey as directed, and answer as accurately as possible.

WHAT ELSE CAN I DO TO HELP?

After the initial survey, you may be eligible to participate in additional research activities. If eligible, you will receive an email and a "Pending Information Request" notification on your PRO Portal "Overview" page. While these additional activities seek to better understand the effects of certain liver diseases, treatments and symptoms, they are not required.

THANK YOU FOR MAKING A DIFFERENCE!

Your participation helps researchers learn more about liver disease, symptoms and treatment, and has the potential to change the face of liver disease for future generations. Together, we are working towards a world free from liver disease.



WE'RE HERE TO SUPPORT YOU

Not Getting Our Emails?

- Check your spam/junk folders
- Verify your email address in the "Personal Profile" section of your PRO Portal
- Contact our support team!

Want to Access Your PRO Portal?

Visit liverpatientregistry.org

Need a Tutorial?

Log in to your PRO Portal and click on "Tutorial" in the top right corner.

Require Technical Support?

Call 413-233-5850

Email support@empiramed.com

Questions About the Registry?

Call 1-800-GO-LIVER

Email registry@liverfoundation.org

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