



RARE LIVER DISEASE PATIENT BILL OF RIGHTS

Your disease does not define you. You are not alone.

As a patient living with a rare liver disease, you have several rights that can empower you throughout your health journey. Although every patient's diagnosis and treatment plan are different, these rights can help you develop better working relationships with the members of your health care team and determine the best path forward for you. If you have any questions or concerns, always talk to your doctor about how to best meet your needs.

As someone living with a rare liver disease, you have the right to ...

1. **Receive the best care and treatment possible** at all points throughout your journey with rare liver disease, with the goal of keeping your liver healthier longer and gaining a better understanding of how your liver functions.
2. **Ask for a second opinion** about your diagnosis and treatment plan. Your primary care provider, or advocacy groups such as the American Liver Foundation or the National Organization for Rare Disorders, can provide links to find specialists at academic medical centers of excellence.
3. **Be your own best advocate for your health** by actively participating in your care, sharing your symptoms and emotions, asking questions, and bringing copies of test results to all appointments. Consider keeping a journal to track how you are feeling each day and share with your healthcare team to help avoid misdiagnosis and/or reduce the time to a diagnosis.
4. **Timely genetic testing** to confirm a diagnosis as early as possible so you and your health care team can plan the most appropriate treatment for you, and to better understand which of your relatives may be at risk for liver disease.
5. **Partner with your doctor to build the right multidisciplinary team of specialists** which may include a hepatologist, gastroenterologist, cardiologist, pulmonologist, and/or nutritionist. Have a team of healthcare providers who listen to you about your concerns and answer your questions so that you can understand what your diagnosis means, what treatment options you can consider, and ways you can manage your symptoms. Choose healthcare providers with whom you can build trust, and who will learn about your rare liver disease with you throughout your journey.

6. **Have access to participate in clinical trials** for the newest therapies and treatment approaches for rare liver diseases. Visit <https://clinicaltrials.gov/>, and talk to your doctor about which clinical trials might be appropriate for you.
7. **Know there is strength in numbers, and that you are not alone.** Build your team of supporters, including family, friends, and health care professionals. Join coalitions like ALF that bring patient voices together to educate physicians and policymakers about living with rare liver disease.
8. **Engage with other rare liver disease patients** for emotional support, either one-on-one or as a member of a patient support group, to help you through your own journey with rare liver disease. Encourage your caregiver to seek peer-to-peer support to help them handle the challenges of their loved one's diagnosis.
9. **Educate others about rare liver disease to reduce misinformation and stigma** that can be associated with it. Share your story with elected officials who can influence health care policy and research funding.
10. **Know what comes next and expect ongoing coordination of your care** between and among your primary care physician, the specialists you see, and other members of your multidisciplinary team.

For more information about rare liver diseases, including resources you may find helpful for your discussions with your healthcare team, visit <https://liverfoundation.org/liver-diseases/rare-disease/>.

To speak directly to a specialist about liver wellness and disease, or for emotional support during times of crisis, contact the American Liver Foundation Helpline at 1-800-465-4837 or info@liverfoundation.org.



Be a Liver of Life!™