

Genetic & Metabolic Liver Disease

About This Resource

These programs and organizations provide trusted information and specialized care options for individuals and families affected by inherited or metabolic liver diseases including Wilson's disease, alpha-1 antitrypsin deficiency, glycogen storage diseases, mitochondrial and urea-cycle disorders, and other rare metabolic conditions. Resources include national foundations, patient registries, clinical-trial networks, and referral centers to help patients access accurate diagnosis and treatment.

National Foundations & Registries

- **Wilson Disease Association (WDA)**

Education, patient registry, and nationwide network of Wilson disease specialists.

 wilsondisease.org

- **Alpha-1 Foundation**

Free confidential testing kits and educational materials for alpha-1 antitrypsin deficiency (AATD).

 alpha1.org

- **National Organization for Rare Disorders (NORD)**

Comprehensive database, patient-assistance programs, and financial resources for rare liver conditions.

 rarediseases.org

- **Global Genes**

Advocacy, peer support, and community connections for people living with rare and genetic diseases.

 globalgenes.org

Specialized Care & Clinical Support (DFW / Texas)

- **Texas Liver Care – Genetic & Metabolic Liver Evaluation**

Comprehensive assessment and long-term management of Wilson disease, alpha-1 antitrypsin deficiency, and other inherited or metabolic liver disorders, including coordination of genetic testing, chelation therapy, nutrition, and transplant evaluation when indicated.

 (682) 427-0200 |  texaslivercare.org

- **UT Southwestern – Metabolic Liver & Genetics Program**

Specialized expertise in rare metabolic and genetic liver diseases.

 (214) 645-1919 |  utsmed.org/conditions-treatments/liver-disease

- **Baylor Scott & White – Liver Disease & Transplant Program**

Multidisciplinary care for inherited and metabolic liver diseases, including Wilson disease and alpha-1 antitrypsin deficiency.

 (214) 820-1756 (Dallas) | (817) 922-1790 (Fort Worth) | (844) 279-3627 (General) |  bswhealth.com/specialties/liver-diseases

For Support & Questions

Texas Liver Care | (682) 427-0200 | TexasLiverCare.org | info@TexasLiverCare.org | 617 Travis Ave, Fort Worth, TX 76104

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- **National Society of Genetic Counselors (NSGC)**

Searchable directory of certified genetic counselors for evaluation, family testing, and reproductive planning.

 nsgc.org

If you need further help finding a liver or genetics specialist, you can search by location and insurance at doctor.webmd.com, or ask your primary care provider or gastroenterologist for a referral to a hepatologist or metabolic specialist.

Research & Clinical Trials

- **ClinicalTrials.gov**

National database of ongoing studies for Wilson disease, alpha-1 antitrypsin deficiency, and other genetic or metabolic liver disorders, including trials focused on new diagnostic tools, chelation therapies, enzyme replacement, and liver-protective treatments.

- **Evidentis Clinical Research**

Clinical trial center offering opportunities to participate in clinical studies related to liver and metabolic health.

 (682) 651-1112 |  evidentisresearch.com

- **Texas Liver Care** can also connect you with studies offered through Evidentis and other collaborating research networks.

Participation in clinical research helps advance future treatments and may expand access to promising therapies under expert medical supervision.

TLC Tips – Living with Genetic & Metabolic Liver Conditions

- Share and safeguard your genetic information — keep copies of your reports and results, and share them with family members or specialists who may need them.
- Ask about research registries or clinical trials that may advance understanding and treatment of your condition.
- Discuss any supplements, herbs, or vitamins with your liver specialist before starting them.
- Seek genetic counseling for family planning, carrier testing, and to better understand your results in context.

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