

## 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](http://wilsondisease.org)

- **Alpha-1 Foundation**

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

 [alpha1.org](http://alpha1.org)


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

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

 [rarediseases.org](http://rarediseases.org)

- **Global Genes**

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

 [globalgenes.org](http://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](http://texaslivercare.org)


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


Specialized expertise in rare metabolic and genetic liver diseases.

 (214) 645-1919 |  [utswmed.org/conditions-treatments/liver-disease](http://utswmed.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](http://bswhealth.com/specialties/liver-diseases)

#### For Support & Questions

Texas Liver Care | (682) 427-0200 | [TexasLiverCare.org](http://TexasLiverCare.org) | [info@TexasLiverCare.org](mailto: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](https://nsgc.org)

*If you need further help finding a liver or genetics specialist, you can search by location and insurance at [doctor.webmd.com](https://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](https://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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