

## A-LiNK: Improving Outcomes in Autoimmune Liver Disease

Status: RECRUITING

### Eligibility Criteria

Sex: ALL

Age:

Healthy Volunteers: This study is NOT accepting healthy volunteers

Inclusion Criteria:

- Clinical diagnosis of autoimmune hepatitis (AIH)
- Clinical diagnosis of primary sclerosing cholangitis (PSC)
- Clinical diagnosis of autoimmune sclerosing cholangitis (ASC)

Exclusion Criteria:

- History of liver transplant

### Conditions & Interventions

Interventions:

OTHER: No interventions

Conditions:

Autoimmune Hepatitis, Primary Sclerosing Cholangitis

Keywords:

Pediatrics, Autoimmune Hepatitis, Primary Sclerosing Cholangitis, Autoimmune Sclerosing Cholangitis, Chronic Liver Disease, End-stage Liver Disease, Clinical Registry, Research Registry, Quality Improvement, Outcomes Research, Comparative Effectiveness Research, Patient Reported Outcomes, Health Services Research

### More Information

Description:

The Autoimmune Liver disease Network for Kids (A-LiNK) is a multi-institutional group with the mission to deliver the best care to kids with pediatric autoimmune liver disease (AILD). This study will establish a shared clinical registry and a learning health network for the participating sites focusing on collecting and transmitting clinical measurement data, information about processes, and participation in an improvement collaborative. Pediatric Autoimmune Hepatitis (AIH) and Primary Sclerosing Cholangitis (PSC), represent a spectrum of AILD which present unique diagnostic and therapeutic challenges. A lack of accepted guidelines for disease monitoring or symptom management results in wide treatment variation with liver transplants indicated in refractory, progressive disease. The aims of A-LiNK are to: 1.) Create a learning health network focused on patient-centered outcomes research characterized by transparent sharing among centers, common priorities, and feasible plans for implementing new practices; 2) shift from traditional investigator-driven study to a patient and family-centered approach, and 3.) improve clinical outcomes and quality of life for pediatric AILD patients.

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Principal Investigator ID:

Phase:

IRB Number:

System ID: NCT05750498

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