What is ChiLDReN?

The Childhood Liver Disease Research Network (ChiLDReN) is a collaborative team of doctors, scientists, nurses, research coordinators, medical facilities, patient support organizations and the National Institutes of Health. The ChiLDReN Network was established by the merging of the Biliary Atresia Research Consortium (BARC) and the Cholestatic Liver Disease Consortium (CLiC), with the addition of studies on cystic fibrosis liver disease (CFLD). The goal of ChiLDReN is to understand the causes of liver disease and to discover new approaches to the diagnosis and treatment of liver diseases in children.

The ChiLDReN Network has clinical sites and research laboratories in the U.S., Canada, and the United Kingdom. These sites are working together to improve the lives of children and families dealing with rare cholestatic liver diseases. ChiLDReN is funded by the National Institutes of Health (NIH), with additional support from the Cystic Fibrosis Foundation (CFF) and the Alpha-1 Foundation.

ChiLDReN can help you:

- Obtain up-to-date information about childhood liver diseases
- Stay up to date with new developments
- Become aware of clinical research and clinical trial opportunities
- Connect with patient support groups
Diseases we study:
The ChiLDReN Network was developed to understand the causes of liver disease and to discover new approaches to the diagnosis and treatment of liver diseases in infants, children, and young adults with cholestasis, and those who undergo liver transplantation. We are currently studying the following cholestatic liver diseases:

- Alagille Syndrome
- Alpha-1 antitrypsin deficiency
- Bile acid synthesis and metabolism defects
- Biliary atresia
- Cystic Fibrosis liver disease (CFLD)
- Idiopathic neonatal hepatitis
- Mitochondrial hepatopathies
- Progressive familial intrahepatic cholestasis (PFIC)

What is Cholestasis?
Cholestasis is a condition in which bile is not flowing properly from the liver to the intestines. Cholestasis is caused by a number of specific childhood diseases, including those listed above. There are several easily identifiable symptoms of cholestasis in children:

- Jaundice (yellow eyes or skin) is caused by a build-up of bile in the liver and the body.
- Pruritus (itching/scratching) also indicates a build-up of bile in the body.
- Poor growth, which is another symptom of cholestasis in some children, is caused by poor intestinal absorption of food, which can often lead to vitamin deficiencies.

There are other symptoms of cholestasis that are related to specific vitamin deficiencies, including:

- bruising or bleeding (vitamin K)
- bone pain or fractures (vitamin D)
- problems with balance and muscle coordination (vitamin E)
- problems with vision (vitamin A)
Our Research:
The ChiLDReN Network has several ongoing studies focused on children that are diagnosed with cholestasis.

Many ChiLDReN studies are natural history studies aimed at acquiring information and data that will provide a better understanding of these rare conditions. Participants will be asked to allow study personnel to obtain information from medical records and an interview, and to collect blood, urine, and tissue samples when clinically indicated, in order to understand the causes of these diseases and to improve the diagnosis and treatment of children with these diseases. All of the information obtained in these studies is confidential and no names or identifying information are used in the study.

The ChiLDReN Network also conducts trials of new medicines and other treatments that may help some of the problems associated with the liver diseases we study.

For information on all active ChiLDReN studies and how you may be able to participate, please go to the Clinical Studies page of the ChiLDReN website:

www.childrennetwork.org

You can also contact any of the ChiLDReN clinical centers (see list below) or contact the ChiLDReN Research Administrator (see contact info above) for more information.

ChiLDReN’s Clinical and Research Centers include:

- **Atlanta** - Children’s Healthcare of Atlanta
- **Chicago** - Ann & Robert H. Lurie Children’s Hospital
- **Cincinnati** - Cincinnati Children’s Hospital Medical Center
- **Denver** - Children’s Hospital Colorado
- **Houston** - Texas Children’s Hospital
- **Indianapolis** - Riley Hospital for Children
- **London** - King’s College Hospital (laboratory facility only)
- **Los Angeles** - Children’s Hospital Los Angeles
- **Philadelphia** - Children’s Hospital of Philadelphia
- **Pittsburgh** - Children’s Hospital of Pittsburgh of UPMC
- **Salt Lake City** - Primary Children’s Hospital/University of Utah
- **San Francisco** - UCSF Benioff Children’s Hospital
- **Seattle** - Seattle Children’s Hospital
- **St. Louis** - Saint Louis University / Cardinal Glennon Children’s Medical Center (Alpha One Antitrypsin Deficiency only)
- **Toronto** - The Hospital for Sick Children
Help when you need it:
Patient support groups and advocacy organizations specializing in cholestatic liver diseases are here to help you. These groups are important partners with the ChiLDReN Network, and are devoted to providing support, resources and services for patients and families. These organizations also promote research into the cause, cure, and treatment of cholestatic liver diseases.

Alagille Syndrome Alliance
503-885-0455
www.alagille.org

Alpha-1 Foundation
305-567-9888
www.alpha-1foundation.org

American Liver Foundation
800-GO LIVER (465-4837)
www.liverfoundation.org

Children's Liver Association for Support Services (CLASS)
877-679-8256
www.classkids.org

Children's Liver Disease Foundation (United Kingdom)
+44 (0) 121 212 3839
http://www.childliverdisease.org/

Cystic Fibrosis Foundation
(301) 951-4422
www.cff.org

PFIC.org
http://pfic.org

United Mitochondrial Disease Foundation
412-793-8077
www.umdf.org

The ChiLDReN website and the ChiLDReN Network are supported by the Data Coordinating Center at:

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